

THE INFLUENCE OF ATTENTION DEFICIT DISORDER ON MOTHER'S
PERCEPTION OF FAMILY STRESS: OR,
"LADY, WHY CAN'T YOU CONTROL YOUR CHILD ?"

By

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Abstract of Dissertation Presented to the Graduate School
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Maternal perceptions of stress vary in the presence of chronic childhood conditions. Behavioral disabilities however are expected to influence the perception of stress differently than medical or physical disorders. This qualitative study consists of interviews with 22 mothers of children with attention deficit disorder (ADD), a behavioral disorder, and 23 mothers of children with cystic fibrosis (CF), a physical disorder. Open-ended questions explore family demands, resources, time use, routines, concerns, and support.

Mothers in both groups report persistent vigilance in the care of their children. This perceived need for vigilance creates an undercurrent of tension in even routine daily activity. Both groups of mothers report problems of decreasing compliance and personal responsibility as the child enters adolescence. Mothers in both groups report a

change in personal priorities and expectations resulting from interaction with their child. Both groups are highly child-focused in daily routines and leisure.

The experiences of CF mothers in this study are consistent with research findings on other chronic conditions. CF mothers report that their extended family provides extensive physical and emotional support. While CF mothers report a persistent emotional sorrow associated with the disease, they are generally able to "normalize" their daily routines. CF mothers describe their children and families as "normal", and are generally positive in their outlook.

The ADD child's behavioral deviations result in social censure of both the child and the mother. With this condition families are not afforded the legitimacy of "illness" or social affirmation for positive parental performance. Thus, mothers of children with ADD have less family support, high perception of child related demands, and tend toward a more negative view of themselves. The demands of ADD are not easily routinized, and few ADD mothers are able to normalize care for their child.

Mothers of adopted children with ADD fared a little better than the biological mothers. While the general patterns were similar, the adoptive mothers reported more support from their extended family and a more positive

sense of personal control. Implications for health care professionals and future research are offered.

INTRODUCTION

Purpose of this Study

The prevalence of chronic childhood conditions is increasing as patterns of childhood morbidity and mortality change (Woodroffe & Glickman, 1993). Advanced medical technologies have increased survival rates and the increased chronicity seen in children in the United States. Ten to 20% of individuals under 18 years of age in the U.S. have chronic health conditions (Jackson & Vessey, 1992). While there is much research pertaining to family stress and associated with childhood disability, few studies have included a comparison group. Although high levels of stress have been reported, there is no comparison standard for critical analysis of the findings. Other studies have included a comparison group of families, but have also lumped several disability types together. In either case it is difficult to determine if the stresses parents report are anomalous, similar across disabilities, or disability specific.

Parents of children with physical disabilities and mental retardation report high levels of stress (Cherry 1989; Crnic, Friedrich, and Greenberg 1983; Dunst, Cooper, and Bolick 1987) which are described in the literature as "crises." The "crises" may center on normal developmental issues or on specific incidents like illness. The initial response to a childhood condition is assumed to be like the crisis type response seen in response to acute illness (Mahon, 1992). When the disease or disability persists, it has been demonstrated that families "normalize" the special demands placed on them by their child's condition (Robinson, 1993; Deatricks, Knafl, & Walsh, 1988). In fact, on ordinary stress measures, families dealing with chronic medical problems do not differ from families without disabled children (Walker, Van Slyke, & Newbrough, 1992; Pless, 1979). Normalization does seem to occur in obviously medical or physical impairments, but does not seem to reliably occur when the childhood disorder has a behavioral manifestation. Only recently has the distinction been made between behavioral and medical disorders in clinical research (Bouma & Schweitzer, 1990; Donenberg & Baker, 1993).

Personal experience with children and families dealing with both types of disabilities led the researcher to believe that the social impact was quite different based on the manifestation of the disorder. The purpose of this

research is to describe the relationship of the childhood conditions known as Attention Deficit Disorder (ADD) and Cystic Fibrosis (CF) with mothers' reports of personal and family stress.

A qualitative approach was selected to explore and describe the different experiences of mothers of disabled children. Both CF and ADD are chronic. The conditions are genetic and present at birth. This is an important distinction because in their reports some of the mothers sampled were not able to separate the child from the disability. This occurred in both groups, and is clearly presented below:

Before you began to deal with [J-.'s ADD] what were your major concerns ? Before we began to deal with his problems was before we had the three little kids . . . it was a different life. Have your concerns [for J-.] changed since his ADDH was identified ? J-. and the ADD are pretty inseparable, my concerns began before the ADD was diagnosed and remain. (AD-13)

Many of the mothers interviewed had difficulty speculating about whether their behaviors were personal accommodations to the disease or simply a normal part of parenting.

The premise of this study is that the childhood behavioral deviations and social sanctions associated with ADD limit the ability to perform and succeed as "normal." The unpredictability and social isolation result in a higher level of routine stress for mothers of children with ADD than that experienced by mothers of children with CF.

Attention Deficit Disorder

Characteristics of the Disorder

ADD is a "psychiatric" disorder rather than a medical one because it manifests in disruptive behavior. But, unlike other disruptive behavior disorders, ADD is believed to have a neurobiologic basis (Hechtman, 1994; Lombroso, Pauls, & Leckman, 1994; Castellanos et al., 1994). This disorder manifests in infancy, although it is seldom diagnosed at this time. It includes a cluster of behavioral deficits that may include a short attention span, poor impulse control (including poor safety awareness), difficulty completing tasks, high levels of motor activity, emotional lability and poor interpersonal awareness.

ADD is problematic because its manifestation is social. There is no single or definitive medical test to identify ADD. It is notoriously difficult to diagnose objectively because the clinical manifestations of the disorder are likely to be modified by the age, culture, milieu, and gender of the child (Aust, 1994; Tynan & Nearing, 1994; Greenblatt, 1994; Weinberg & Brumback, 1992).

ADD is disproportionately reported in boys from upper and middle class families (Greenblatt, 1994). There is no reason to believe that the actual incidence is higher among the more affluent, but rather these are the individuals with

the financial resources to pursue the diagnoses. Nearly six times as many boys as girls are diagnosed with ADD, although in adulthood the incidence is nearly equal in the two genders (Biederman et al., 1994). It has been posited that girls are significantly underdiagnosed with ADD at this time (Biederman et al., 1994; Greenblatt, 1994).

A lack of recognition of attention deficit as a "real" disorder is widely noted in the educational and health care communities (Kasten, Coury, & Heron, 1992; Hunsucker, 1988; Selekman, 1991). This is compounded by the subjective and often inadequate testing to determine the basis of a child's behavior problem (Halperin, 1991; Aust, 1994; Tynan & Nearing, 1994). As Weinberg and Brumback (1992) demonstrate, the persistent public outcry about the use of this diagnosis as an excuse for antisocial behavior is often justified. The inconsistencies in identification, testing, and treatment of this disorder add to the overall public hostility towards ADD (Shealy, 1994; Halperin, 1991; Kasten, Coury, & Heron, 1992; Leifer, 1990).

ADHD, the most common type of the disorder, includes high activity levels and often aggression. This disorder is characterized by "developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity" (DSM-III-R, 1987, p. 50). Children who have ADD without hyperactivity are most often described as "spacy." They may have trouble at school but are not disruptive. The hyperactive children

are the ones most likely to be labelled "bad." Because their children are "bad," and their behavior defies all usual parenting strategies, ADDH is expected to be especially stress producing for primary caretakers.

History and Social Issues

ADD is the most common behavioral disorder in childhood (Friedman & Doyal, 1992). It affects up to 20% of all school-aged children (Shealy, 1994). The inattentive, impulsive and sometimes hyperactive behavior seen in children described as ADD are not new, but seem to be increasingly dysfunctional in today's classroom settings. In a less individualistic, information-driven society a poor ability to work independently at tasks may not be disabling. The aggressive and disruptive behaviors associated with ADDH are especially socially censured.

ADD and ADD with hyperactivity (ADDH) have only recently been described as discrete disorders (Diagnostic and Statistical Manual of Mental Disorders: DSM-III, 1980). Prior to 1980, there were a number of pediatric labels that included the characteristics of ADD. The most widely used were Minimal Brain Dysfunction and Hyperkinesis. The fact that the diagnostic label is new leads people to believe the condition is also new. This is not the case.

Some suggest that ADD is a socially constructed disorder (Leifer, 1990; Illich, 1976). It is easy to see that in an agrarian society, attentional difficulties are unlikely to be considered disabling. In fact, even in our industrialized society there is little acceptance of attention deficit as a disability. This "disease" manifests as a child's "bad" behavior. It is a common assumption that the behavior is the result of inadequacies in the parent or teacher. While professional evaluation can distinguish the mismanaged child from the ADD child, the difference is not clear to most lay people. So contentious is this issue that recent issues of popular magazines like Newsweek and Time have done articles on ADD.

Accepting that ADD is real does not always mean accepting that the medical approach to intervention. So what if persons with ADD think and react in totally different ways than the mainstream? Why attach a medical label to this differentness? This thinking emphasizes that society needs diversity and different thinkers. Among this school of thought, it may be considered heinous and coercive to advocate the use of medications in children to achieve "normal" behavior (Leifer, 1990; Illich, 1976).

Interventions and other Controversies

In addition to a nonstandardized diagnostic process, there are disputes as to when to intervene and at what level. Many children are identified for testing by teacher observation in elementary schools. This approach relies on the skill (and beliefs) of the teacher and the expectations placed on the child. If the child is not expected to perform well in school (because of race, gender, family situation, or some other reason), a difficulty attending in class is likely to be overlooked.

Once diagnosed, there is no standard intervention for this disorder. Stimulant medication is usually the first intervention suggested. Although about 90% of children with this diagnosis are medicated, the decision to use the medication is usually difficult for parents (Reid, Maag, Vasa, & Wright, 1994; Walker et al., 1988). For many persons, the medication alone provides adequate resolution of the behavior problems. As noted earlier, while the use of medications for ADD is widely accepted in the medical community, it continues to receive much social criticism (Milich et al., 1989; Johnson, 1988; Summers & Caplan, 1987).

In addition to medication, behavior management and psychotherapy for both the child and parents are often recommended (Cousins & Weiss, 1993; Leung et al., 1994;

Beitchman, Inglis, & Schachter, 1992; Long, Rickert, & Ashcraft, 1993). Cognitive and sensorimotor therapies are appropriate in some cases, when the child also lacks coordination or has difficulty using information from the environment (Fisher, Murray, & Bundy, 1991; Kleinman & Stalcup, 1991; Whalen & Henker, 1986). The use of these other interventions is poorly researched. The type and quality of interventions available are variable and non-pharmaceutical treatments for ADD are seldom included in routine health insurance coverage.

The Family and ADD

ADD is described in the DSM-III-R (1987) as a "disruptive behavior disorder." Children with ADD interact with and exasperate everyone in their environment. Anyone who may be subjected to a range of disruptive behavior ranging from spacy disorganization to physical aggression. In this study there were seven (of 44) mothers who described their child using the word "bad." Of these six children were diagnosed with ADDH; the remaining one was a CF child suspected of having ADDH as well.

Further complicating things, there is a strong genetic pattern in the incidence of ADD (Hechtman, 1994; Lombroso, Pauls, & Leckman, 1994; Faraone et al., 1993; Biederman et al., 1992). Adult family members may have the same

difficulty with impulse control and social behavior that their children face. Rather than adding to their understanding of the child, this often seems to result in impatient, aggressive, depressed, or substance abusing parents (Marshall et al., 1990, Cantwell, 1988).

Epidemiologic studies demonstrate that persons with ADDH often have an additional psychiatric diagnoses. Common concurrent problems associated with ADDH are the other common externalizing psychiatric conditions of conduct disorder, oppositional-defiant disorder, and also both mood (depression), and anxiety disorders (Biederman et al., 1992).

Although families with ADD in general are not significantly different in their functioning when compared to established norms, there are significant differences in functioning between ADD families dealing with hyperactivity and those who are not.

Those families of children with ADD only, without the additional problem of hyperactivity or aggressive symptoms, reported the highest level of functioning, and a larger percentage of families whose child had hyperactivity or hyperactivity plus aggression were extreme in their functioning. Age of the child was related to poorer family functioning, suggesting a cumulative negative effect on the family in dealing with the child over time. In combination with parents' perception of impulsivity/hyperactivity, the age of the child was significant in predicting family functioning. (Lewis, 1991 p. vi)

Parents of ADDH children reported fewer extended family contacts and described these as less helpful than comparison

families (Cunningham, Benness, & Siegal, 1988). The behavioral sequelae of ADD result in a public perception of ineffective parental control (Friedman & Doyal, 1992).

Cystic Fibrosis

History and Social Issues

Cystic Fibrosis (CF) was first described in the medical literature in the 1940s. It is the most common lethal genetic illness in white children (McMullen, 1992). CF occurs among blacks at the same rate as in whites, but is less common among this group than sickle cell anemia. Genetic research has provided a series of dramatic breakthroughs in the treatment of this disorder. The CF gene was isolated in 1989 (CF Foundation, 1989). Other advances include the availability of a test to determine a potential parent's CF carrier status (Miedzybrodzka et al., 1994) and prenatal tests to determine carrier status (Lieu, Watson, & Washington, 1994). The new genetic information has led to the development of several new approaches to intervention. The analysis of mucous build-up in the lungs has led to the use of an inhaled enzyme therapy to reduce congestion (Crystal et al., 1994). There is promise of in-vitro and in-vivo gene therapy to genetically alter diseased cells within the lung of the patient (Mittereder et al.,

1994; Brody et al., 1994). Studies on mice promise a genetic therapy for intestinal defects common to CF (Zhou et al., 1994).

The median survival age for children with CF has grown from about 2 to 29 years of age. It is conceivable that in the next ten years cystic fibrosis will be a chronic, but no longer fatal disorder. There is a whole cohort of young people with CF who were born with a life expectancy of less than 17 years, but who are moving into adulthood and adult decisions.

Characteristics of the Disorder

CF was selected for this study because it, like ADD manifests at (or near) the time of birth, is invisible to the casual observer, and requires extensive parental accommodation. The fact that school age children with CF are often healthy and active, while requiring ongoing treatment, makes it comparable to ADD because it is socially "invisible." CF is much less common than ADD, occurring in approximately one in every two thousand births (McMullen, 1992). CF is not associated with intellectual, social or behavioral abnormalities. The social and behavioral differences between ADD and CF are the focus of group comparison in this research.

CF affects multiple organs throughout the body, most particularly the pulmonary and digestive systems. Common clinical problems are pancreatic enzyme deficiency, progressive chronic obstructive lung disease, and sweat gland dysfunction (McMullin, 1992).

A primary concern of families with children who have CF are the regular hospitalizations such persons need, "tune-ups" they are called, averaging about two weeks one to two times a year. Ongoing issues that worry the families are growth delays, drug resistant bacteria, bowel problems, coughs and wheezing (McCollum & Gibson, 1970).

Children with CF are especially susceptible to disease complications, like lung infections. Ordinary childhood illnesses like chicken pox often lead to hospitalization because of the potential exacerbation of pulmonary symptoms (McMullin, 1992). Any lung infection can become fatal for a child with CF. Mothers in this study reported extreme care to limit their child's exposure to colds and other diseases. The most common concern expressed about their child starting school was the increased exposure to disease.

Interventions

Unlike ADD, there is no medical or social controversy about the existence or medical management of CF. Diagnosis is definitive. Treatment of CF is equally clear cut.

Children need to take pancreatic enzymes each time they eat, and require a high caloric intake. Their susceptibility to lung infections necessitates periodic courses of antibiotics and occasional hospitalization. In most cases, ongoing chest percussion and inhaled medication are used one to two times daily to clear bronchial obstruction (McMullen, 1992).

Aerobic exercise and physical activity are encouraged to help maintain pulmonary efficiency. Many children receive postural drainage and chest percussion two to four times daily (Williams, 1994). New treatments for CF offer more than symptomatic relief. In cases of extensive lung disease, some success has been documented with lung transplantation. One of the new genetic treatments introduces normal human DNA for lung fluids into the lung lining of the person with CF. This type of treatment offers families more hope for the future, but adds some complex new medical procedures for them to learn.

CF has a clearly defined progression of symptoms although the rate of deterioration varies widely. For the most part, elementary school children have a truly invisible disorder. By late adolescence, many children acquire a distinctive cough, wheezing, and decreased exercise tolerance.

Children and families with CF have access to extensive medical and social support through the health care system. In the state of Florida all persons with CF have their

specialized health care needs (routine appointments, hospitalizations, medication, counseling, etc.) provided through a few specialized clinics that contract with Children's Medical Services of Florida (CMS). CMS is a Title 5 agency, designed to provide case management services for financially eligible families. When private health insurance exists, the policy is used to pay for services. In many cases health insurance companies refuse to insure persons with CF. CMS also provides supplemental care to indigents who are covered by Medicaid, and care on a sliding scale to other clients.

All the mothers interviewed were drawn from the same CMS district. In this district CMS will pay for the clinic visits, hospitalizations, and prescriptions for any child with CF. Unlike those with ADD, children with CF are assured payment for basic health care expenses.

The Family and CF

The most distinctive issue that families with CF face is the emotional difficulties associated with their child's prognosis. The daily care of CF is extensive, but routine. Studies of families with CF indicate normal family interactions and typical daily function (Sawyer, 1992; Gibson, 1988; Phillips et al., 1985). There is little social isolation associated with CF. Parents report

extensive use of social resources, including support from the extended family, assistance from the pulmonary clinic, and contact with other parents (Gibson, 1988).

There is some evidence that adolescents and young adults with CF are less responsible for themselves than are their healthy peers. The mothers of these teens report fear for their child. For many, concern about early death haunts daily family decision making. In trying to create a normal home environment, mothers of the CF child worry about the effects of their fears on the well-being of the family (Nuttall & Nicholes, 1992). One of the most disruptive aspects of CF management is the need for frequent hospitalizations, which disrupt routines and add stress to all family members. Specific problems associated with hospitalizations include "well" child care, transportation, school expectations, vacations, and time-off from employment.

The focus of this study is on the mothers of impaired children. The mothers' feelings about the condition and about themselves in relation to the condition provides a basis for explaining disability specific challenges. It is expected that the stigma of poor parenting will influence maternal behavior and beliefs.

LITERATURE REVIEW

The Social Construction of the Family

In the face of chronic challenge, the perception of "life as normal" is highly valued. Normalization provides a model of adaptation to long term disability. Normalization theory is based in the belief that individuals (in this case mothers) assimilate and make meaning of their lives, and then act on their own constructions. "This process becomes reciprocal as action then serves to shape meaning or belief . . . people construct meaning by structuring their experience into stories . . . the story is [then] the context in which life events are interpreted." (Robinson, 1993, p.8)

Parents of children with ongoing problems are advised to raise their children as they would children who were not disabled. This encourages the development of the dominant story as one of a normal family leading a normal life. With normalization, special procedures and adaptations for the child become routine or habitual over time (Deatrick, Knafl, & Walsh, 1988; Knafl & Deatrick, 1986; Gibson, 1988). The description of complex daily care routines as "normal"

characterizes assimilation of the "differentness" and may be an indication of positive adjustment to long term disability.

Families continuously create and elaborate on family "stories." Family stories provide an account of family history and creates a context for interpretation of current family actions. Families select only those parts of the actual events that support the prevailing story to assimilate into their daily lives. The prevalent family story seen in families positively adjusted to dealing with a chronically ill family member is the story of life "as normal" (Robinson, 1993; Knafl & Deatrick, 1986; Seligman & Darling, 1989).

The life "as normal" story in chronic illness glosses over atypical family demands and routines. The behaviors specific to managing the disease are presented as inconsequential in telling the family story. When a family embraces a life "as normal" story they may no longer be sensitive to all the ways they accommodate the disability.

Normalization is the incorporation of a life "as normal" story into the family consciousness. Normalization is considered a positive adaptation to daily demands that are atypical. A key to normalization is that the daily demands associated with the disability can be routinized, and therefore performed without thought or emotional challenge (Knafl & Deatrick, 1986). Threats to the

development of a self-perception of normality are isolation, uncertainty, and unpredictability (Angst, 1992).

All families socially construct themselves in the manner described above. Gallimore et al. (1989) elaborated on this process to suggest that a family's environment offers a limited array of resources and constraints. Within the explanation offered by this theory, ecocultural theory, families work within these constraint to create an acceptable family story. In other words, families construct "niches" or activity settings in which they can build their "life as normal story". In this research, the search for the perfect "school" was a goal of many respondents. A very high proportion of the ADD children in income brackets over \$50,000 were in private schools that provided environments in which the child could be "normal." This ecocultural niche approach is believed to affirm family patterns of action in the face of social pressures. The niche allows the approximation of "normal" within the constraints faced by the family and the child.

Ecocultural theory operates to analyze families beyond their self-perception of normalcy. Of the 23 families having a child with CF, 17 said that friends and family viewed their child as normal, ordinary, or in terms of specific attributes like outgoing or serious. Only one of the ADD mothers used the word normal and one used the word ordinary in describing their child. Mothers dealing with

ADD are expected to have difficulty normalizing the demands placed upon them. The impulsiveness and disorganization common to the child with ADD makes it difficult to establish or maintain routines.

A focus on the social construction of the family "as normal" will be used in the analysis of this data to help determine whether the behavior and social adaptations of either group supports or extends the theory of normalization. The ecocultural theory will be considered because it offers a strategy for creating a semblance of "normal" when normal is not possible under existing circumstances. In ecocultural theory there is a family constructed set of beliefs, behaviors and routines that promulgate the family self-perception. This family self-perception could be adaptive, neutral, or maladaptive.

The Mother Role

Individuals maintain a variety of roles in the family group. Those roles are likely to change with the social and environmental demands of the situation. This research seeks insight into the subjective role experience of parenting a chronically impaired child. Differing gender and cultural expectations are likely to affect an individual's perception of their parent role. While other family members may do much parenting, this research focuses on the parenting

experience of mothers. Mothers are consistently more involved in the daily lives of their children (Thompson & Walker, 1991) and are more available in the clinical settings where this research is set.

The role of mother is value laden and includes both the daily work of child care and the larger social meaning of having children (Boulton, 1983). Societal images of motherhood include that 1) a mother enjoys her child, 2) a mother intuitively knows what to do for her child, 3) a mother cares for her child without ambivalence, and 4) the mother devotes herself first to her child's needs (Thompson & Walker, 1991). This role is subjective and "ongoingly maintained, modified and reconstructed" (Berger & Luckmann, 1967, p. 172). Social ideals about motherhood are germane to this study as an explanation for the choices and behavior reported.

Ideals of motherhood are clearly socially constructed (Margolis, 1984; Hunter College Women's Studies Collective, 1983; Berger & Luckmann, 1967). The presentation of motherhood as either a full-time occupation or a "job" is a twentieth century construction (Bernard, 1974; Margolis, 1984). Around the turn of the century there was a trend toward the "professionalization of motherhood" (Margolis, 1984, p.40), marked by widespread marketing of materials to train appropriate mothering. Using the gestalt presented in the popular media, including Working Mother magazine, Parent

magazine, and Parenting magazine, because of economic need mothers are now expected to work outside the home, yet be committed to "professional" mothering. Economic need rather than career aspiration is often cited as a reason to work, with the ideal of full-time at home mothering. In addition, mothers tend to personalize their child's successes, failures, and sometimes even illnesses. Margolis (1984) noted that "mothers are not only blamed for their children's psychological and behavioral problems but sometimes for their physical problems as well" (p. 259).

Challenges to the Mother Role

Gilgun, Daly, and Handel (1992) describe parenting as an "ongoing, and at times unpredictable, process of personal change [that] occurs against the backdrop of a typified, taken-for-granted reality" (p. 105). Most of the mothers studied describe a process of personal change in response to their child. Their overall role expectations and sense of personal control are challenged by the demands of a chronically impaired child.

The reciprocal nature of parent-child relations results in both the expected pattern of a parent shaping a child's behavior, and to the less discussed issue of the child shaping the parent's behavior. Ways in which parents accommodate children include changes in routine, work or

career decisions, and time spent at home. In this study any of this type of accommodation will be considered to impact the mother's sense of "mothering". The process of redefining maternal roles in the face of chronic childhood disabilities is expected to force the mother to take stock of herself and her expectations.

The challenge of chronic illness often results in either a revised maternal identity that contributes to a perception of normality, or to a pattern of ongoing crises. In both samples the behaviors that mothers needed to manage their child were atypical. For example, in both cases mothers felt that they maintained a higher level of child vigilance for their impaired child than other mothers.

The greater the deviations in the mother's role performance and expectations from the cultural norms, the higher the probability that that individual will experience stress. Also, because child outcomes are linked to societal perceptions of mothering, the failure of a child to develop in expected ways challenges the mother's perception of competence. Some mothers respond to these challenges with compulsive adhesion to treatment rituals. By assuring that their child gets the best, most extensive intervention routines the mother is convinced she is a good mother, in spite of her imperfect child. If the routine she adopts as "best treatment" is not accepted by health care practitioners, the mother may feel that the health care

provider is denouncing her mother role. A common example of this is a special sugar-free additive-free diet to treat hyperactivity. Maintaining the diet is requires much maternal effort (baking bread and such), and refutation of this approach may constitute a challenge to that individual's mother role. This sort of challenge is likely to cause vulnerability and limit the potential for adaptation unless it is handled carefully and sensitively.

Research on children with chronic medical conditions, including cystic fibrosis (McCubbin, 1984), developmental disabilities (Freidrich, Cohen, & Wilturner, 1987; Dunst, Cooper, & Bolick, 1987), and physical disability (Kazak, 1986; Pless & Pinkerton, 1975; Stowell, 1987) consistently links the adaptive processes of families to those in the impaired child. In those instances where the child does not behave as socially expected, the mother's role performance is challenged.

Parents of atypical children often deal with both exaggerated normal stresses, like the increased vigilance reported, and some stresses unique to their child's disability, like the management of inhaled and IV medications in CF (Failla & Jones, 1991; Cherry, 1989; Slater & Wikler, 1986). This research will describe the types of concerns and pressures reported by mothers of children with CF and mothers of children with ADD.

The Resiliency Model of Family Stress

The family unit, and the mother's role within it, are determinant in the successful provision of health care services to children (Pless & Pinkerton, 1976; Patterson, McCubbin, & Warwick, 1990). In most cases the mother is the primary caretaker, and the mother's understanding of and commitment to her child's intervention are salient predictors of child health outcomes (McCubbin et al., 1983; McCubbin & Thompson, 1991; Patterson, McCubbin, & Warwick, 1990).

The *Resiliency Model of Family Stress and Adaptation* (RMFSA) will be used to describe and analyze the dynamic influences of children's disabilities on a family system. The RMFSA works on these assumptions: 1) families face hardships and changes as a natural aspect of family life; 2) families foster the growth and development of family members; 3) families protect themselves from unexplained or non-normative stressors; 4) families adapt to reduce disruption following a family crisis; and 5) families benefit from and contribute to the network of resources in the community (McCubbin & Thompson, 1991, p. 3).

The RMFSA describes two phases in a family's response to life changes and challenges. The adjustment phase is the first response to an acute stressor. *Figure 1* outlines the adjustment phase of this model. As illustrated the outcome

of the adjustment phase is either adaptation or exhaustion. Adaptation in this phase usually involves a coping strategy like avoidance, elimination, or assimilation (McCubbin & Thompson, 1991). Adjustment is a short term response. This is the process through which the family responds to ordinary life changes and transitions.

The adaptation phase extends the focus to the family's efforts over time. Background stressors are chronic unresolved pressures on the family. Background stress plays a small role in the adjustment phase, and a large role in the adaptation stage. Common background stresses include concerns about family financial limitations, the age of the child, and the stigma associated with chronic disability.

Pile-up of Stressors

The assimilation of everyday pressures and day-to-day crises creates an accumulation of unresolved issues, described by McCubbin and Thompson (1991) as a pile-up of concurrent or prior stressors. This pile-up provides a "background" level of stress upon which new events accumulate. The accumulation of background stress is associated with maladjustment in the adjustment phase of RMFSA. From this the family moves into a crisis state that results in either adaptation or exhaustion.

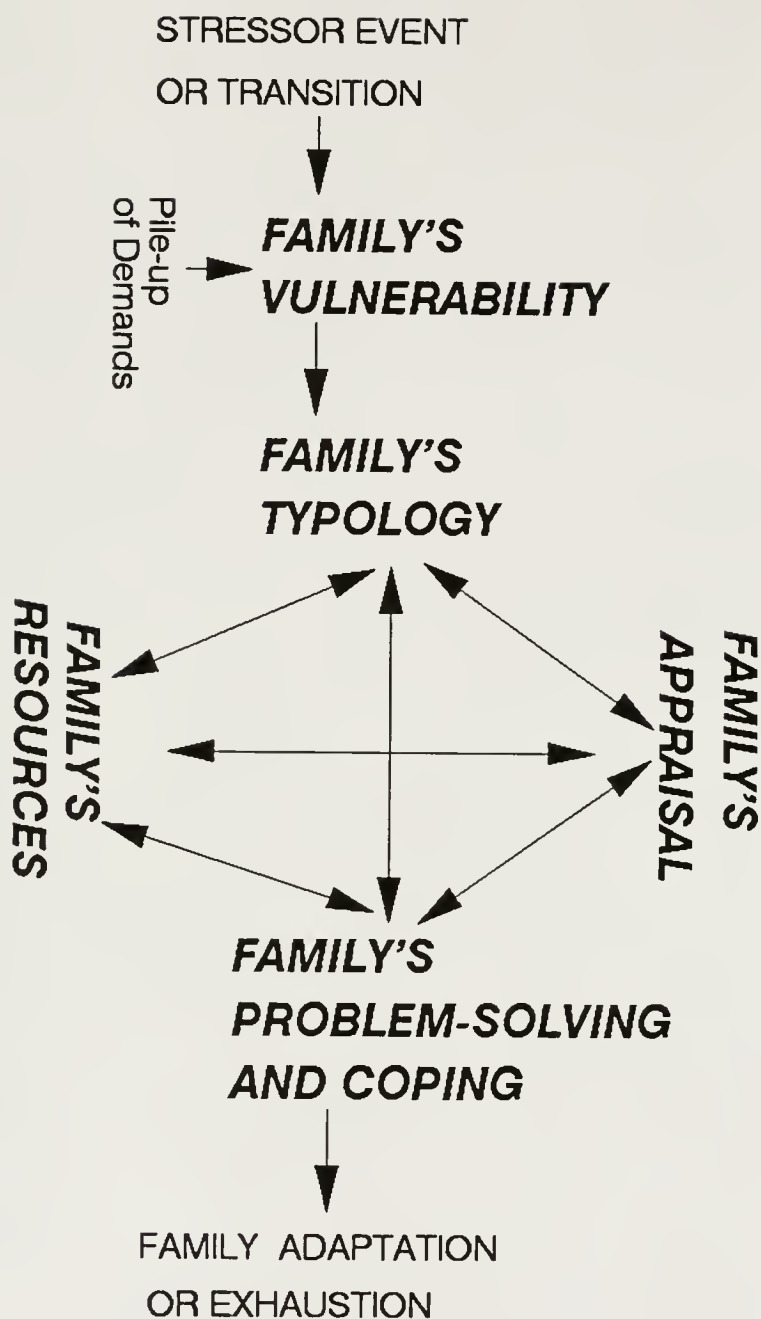


Figure 1 Adjustment Phase of the RMFSA

Stress pile-up may include a specific crisis situation such as a divorce, the addition of a family member, or a change in the work status of a family member. It may also include normative transitions like the high need for nurturance and supervision with young children, a desire to pursue a career, or a change in the extended family. Normative transitions given a particular focus in this research included a child entering school, transitions in school (i.e. from elementary school to middle school), and adolescence.

Prior strains are the residue of earlier unresolved crises. There may also be prior strains inherent in ongoing family roles. This pressure on the family due to role ambiguities is important to consider in this study. If the role of "parent" is indeed a loosely proscribed social construction, then parents would perceive more role strain if their family was socially atypical. A family with an ill family member, that still functioned within the bounds of social expectations is unlikely to experience this type of role strain. Stress pile-up and role strain negatively impact family function (McCubbin & Thompson, 1991; Lavee, McCubbin, and Olson, 1992).

Family Vulnerability

Family vulnerability is a dynamic response threshold determining whether a family perceives specific events or demands to be threatening. Family vulnerability varies with the amount of demands and stressors experienced and the family resource level (McCubbin & Thompson, 1991; Mahon, 1992; Kazak, 1989). All families experience some degree of vulnerability and periodically experience situational hardships.

In this model the stressor event or transition starts the process. This stressor interacts with the family's vulnerability. The concurrent pile-up of demands on the family determines vulnerability. Demands include stressors, strains, transitions, and the family's life cycle stage. These factors are: the specific characteristics of the child's disorder, cumulation of both background and personal stresses, family resources, and the social network of the family. Family vulnerability is the outcome of the interplay between family stresses and family resources. High vulnerability suggests high stress with relatively low resources.

This interaction of stresses, strains, and family vulnerability occurs in the family adjustment process. Adjustment is a short-term response to manage life changes, transitions, and demands. This research will consider the

family's current situational stresses in order to distinguish ordinary stress from issues specific to disability. Social network will also be considered because the impact of personal stressors is expected to be reduced in the presence of social support (Cobb 1982; Pilsuk & Parks 1983).

The adaptation phase focuses on family problem-solving and efforts over time to recover from and minimize crisis situations. Because the chronic childhood conditions being studied include daily adaptations over a long period of time, this portion of the RMFSA will be emphasized in this research. Adaptation is a dynamic response building on and interacting with the adjustment phase of the model. For this reason there are many redundant aspects of Figure 1 and Figure 2. Figure 2 illustrates the adaptation phase of the RMFSA.

Figure 2 begins where the adjustment phase leaves off, with either family adaptation or exhaustion. In this phase family values, family coherence, community, and friend support are expected to play important roles. The outcome of this phase is a balance between individual family members and the family unit and a fit between the family unit and the community of which the family is a part.

The components of this model, vulnerability, resources, resiliency, and adaptation were used in determining interview content in this study. Some of the constructs in

the RMFSA were not measured. Family typology was not considered because in this research there was no intent to predict or quantify family function.

The Sick Role

In the general population the identification of a specific disease process (as in cancer) sanctions different social behavior. Classically, the "sick role" affords a release from usual work and self-care expectations (Maddox & Glass, 1989; Parsons, 1975). The sick role conception focuses on individuals with some illness and assumes that the illness will not persist. The extension of the sick role to families is presumed because of the pre-eminence of the mother-child dyad socially.

"Disease" Boundary

In the boundaries of the sick role described by Parsons (1951), a "disease" is a condition in which the person has an incapacity that is beyond his or her control. The sick individual (or mother-child dyad) is not responsible for either causing or maintaining the child's illness. CF is a "disease" within this definition. Although it is genetic, CF is recessive. None of the mothers in the study believed

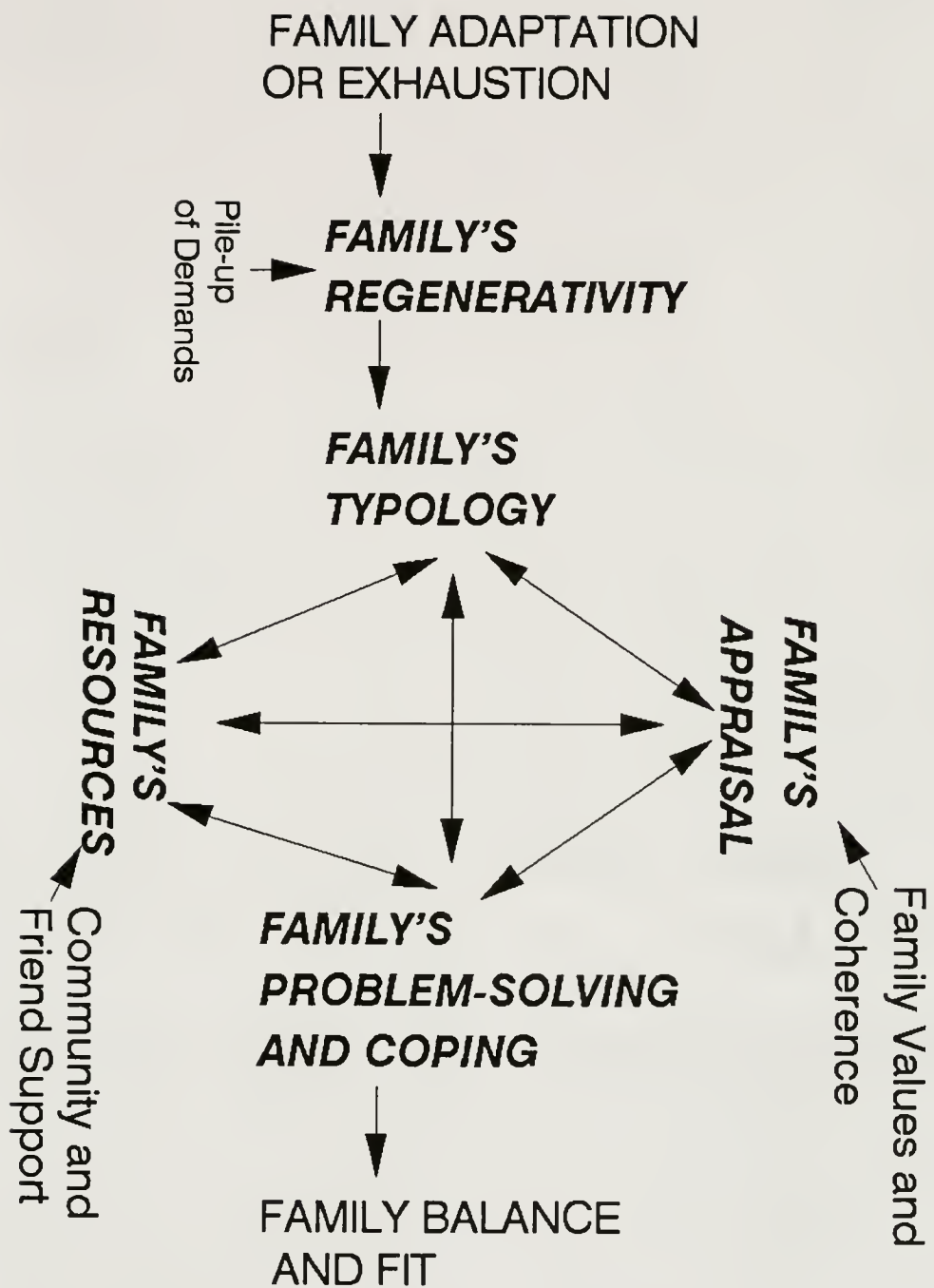


Figure 2 The Adaptation Phase of the RMFSA

that they were at risk for having a CF child, and none of the mothers had another child (with the same father) after their child was diagnosed with CF. The condition is known to be incurable, so while the mother's behavior may extend or shorten a child's life, the mother cannot through exemplary behavior, eliminate the problem.

Is ADD a condition that is beyond the control of the mother and/or the child? This problem is central to this research. ADD has been medically identified, and is treated biochemically. But is the behavior manifested outside of possible control by the child or the mother? ADD is genetic and the exact means of genetic transmission are unknown, so parents having these children cannot be considered "at fault." Most of the ADD children were not diagnosed until after they had started school, and although the families with ADD had more children, those mothers also did not continue having children after their child was diagnosed. Like CF, the condition is incurable, at least in neurophysiological terms. This is where the problem of public opinion occurs for ADD. Mothers are considered responsible for their child's behavior and ADD children often misbehave. Society and even many of the mothers themselves feel that control of behavior is a mark of good character and a social responsibility. Impulsive, aggressive, and disruptive behaviors are condemned widely. The medical explanation does not seem to free either the

children or their mothers from socially accepted behavior standards.

"Treatment" Boundary

Another boundary of the sick role is that the sick person recognize that illness is an undesirable state and must cooperate with efforts at treatment. Important to this research is the condition that all members of the sick person's family have an obligation to seek and cooperate with competent medical help.

As before, CF fits easily within this constraint. Because the children do not live without persistent and aggressive medical intervention, they are living acknowledgements of cooperation with treatment. The CF mothers reported lots of social affirmation, little volunteered advice, and little unhelpful behavior in the community. ADD presents a more mixed picture.

There is no widespread agreement on the treatment of ADD. In the general public, as many condemn medicating the children as support it. Mothers in this study reported testing for allergies, trying special diets, and attempting a variety of interventions through health care providers including parenting classes, anger management groups, and occupational therapy. In spite of medical research, the public opinion persists that ADD is not a disease but a

manifestation of poor parenting and poor child self-discipline.

Because it is not recognized as a "disease," treatment with stimulant medication (the recommended medical approach) is seen as a crutch or a way to hide the real problem. With ADD, the use of medically recommended treatment is not always socially affirmed. With the lack of "disease" status families dealing with ADD do not get a release from social expectations for child or parental behavior. There are diverse approaches to treatment of ADD. These treatments also, may not be socially sanctioned, depending on the beliefs of the individuals involved. For this reason efforts toward treatment may not be acknowledged.

The sick role perspective considers illness a form of social deviance. In this viewpoint families dealing with chronic childhood illness can be considered deviant. The natural tendency to move away from social deviance toward "normal" will provide insight into the analysis of mother's concerns and behaviors in meeting her child's health needs. It is expected that community and other social supports will be more available to a family that is deviant because of "illness" than a family that is "deviant" without the sanction of the sick role. In keeping with this theory, we would expect families with CF will receive more social affirmation and support than families with ADD. Most families in both groups remarked that their children's

disease was "invisible" and they only told "people who needed to know" about it. They said that they wanted their family and their child to be treated normally. In this instance, the CF families again will have the more positive experience. CF children look and behave normally. Social reaction to them will affirm the families sense of normalcy. The disruptive social behavior common to children with ADD with result in negative social pressures and a family sense of deviance.

Normalization

Viewed in the context of the sick role and deviance, normalization can be considered an adaptation to chronic illness that allows a family to make the transition from social deviance to social normalcy. Literature on chronicity states that families "normalize" the special demands placed on them by their child's chronic condition (Robinson, 1993). The "normalization" process is an adaptive response common to both adult and childhood conditions requiring special routines or medical management.

Normalization is "the constant process of actively accommodating the changing physical and emotional needs of the child or adolescent" (Deatrick, Knafl, & Walsh, 1988, p.17). Families actively construct a "normal" approach to their special child. Research on families with a mentally

retarded child reports that social construction occurs both within the family and in the society at large. The overall goal of normalization is to "integrate the child into the family rather than making him or her a 'special nucleus'" (Deatrick, Knafl, & Walsh, 1988, p.17). Normalization is an ongoing process that involves both conscious and unconscious behavior strategies to deal with activities of daily living; discipline; socialization of the child; family recreation and other "normal" childhood activities like school.

Gallimore et al. (1989) develop a similar theory involving family construction of beliefs about everyday routines. In the Ecocultural theory beliefs, values, goals and resources of the family are mediated through daily routine. In both normalization and ecocultural theory the family is an active participant in developing and maintaining an atmosphere that enhances the perception of "life as normal."

A perception of family life as normal seems largely based on the establishment of order and routines in daily activities. Medical treatments that need to be done become assimilated into normal wake-up and bedtime activities. When activities cannot be routinized by time of day, they may be routinized in what the mother "routinely" carries in her purse for interventions or in a highly structured behavioral routine. Most of the treatment of CF lends itself to routinization. The behaviors associated with ADD are less

amenable because they are interactive in terms of time, place, objects, and persons the child comes into contact with. Because families cannot totally control these influences, the treatment of ADD is not easily routinized.

Model of Human Occupation

Because roles, activities of daily living, and personal routines are the foundation of normalization, the Model of Human Occupation (MOHO)(Kielhofner, 1985) provides a useful tool for data analysis. MOHO presents a detailed framework for the analysis of personal roles, routines and habits. Each individual is determined to have a variety of work, play, and daily living roles that are unique based on their beliefs, experiences and environments. Role expectations are dynamic and environmentally sensitive (Barris et al., 1985). Using the language of theories mentioned earlier in this text, roles are socially constructed and may vary from hospital to the classroom to other settings.

Occupational Role Analysis

MOHO assumes that people choose and participate in roles that are socially recognized based on their values, interests, abilities, and social pressures. This assumption is not consistent with the previously described role of

mother. Not everyone who engages in parenting specifically chose that role, and few of the mothers in this study chose to parent a chronically ill child. Unlike the role of worker, parenting is a loosely defined social role for which there is no specific delineation of behaviors that define competency. Although parenting roles fall outside the role assumptions stated in MOHO, the analysis of volition and environmental press contribute possible explanations for the perceptions of the mothers in this sample.

The concepts "sick role" and normalization are not components of MOHO, but are in some ways consistent with it. A model of occupational role analysis was developed by Cubie (1985). This model includes five discrete aspects of roles: environment as created by the occupation, motivation, the organization of behavior, the development of skill, and output of the behavior. Successful performance of social roles is seen as the result of efficient, organized occupational behaviors (i.e., play activities, self-care activities, and work). Optimally, these behaviors are organized into patterns or routines that become habit. In theory, by relegating everyday behaviors to habit, the person is free to direct more of their energy to explore, learn, and challenge their environment.

Parents of chronically ill children must look outside traditional social roles to pattern and organize their behaviors. The "sick role" affirms the decision to abort

career plans and stay home with the "sick" child. It also could be used to de-emphasize ordinary behavior expectations of childhood. Normalization behavior of mothers with chronically ill children should be conducive to positive adaptation and family function.

Environmental Press

MOHO was not constructed to address the issues of families, but addresses the family as an aspect in the individual's environment. *Figure 3* presents MOHO's four conceptual layers of environmental influence on the individual. In this model the family, the school, and the health care system are seen as part of the social groups and organizations layer. Environmental press is the "environmental expectations for certain behavior" (Barris et al., 1985). Press is a useful construct in this research as it influences the habits, routines, and role expectations of the individual.

The environmental press for mothers of children in the two groups are only slightly different. Expectations of good parenting and social roles remain stable for both groups of mothers. The press that the community exerts on the mother, and the reciprocal press of the child on the mother are the interactions of interest in this research. It is hypothesized that the social, school, and family press

is very different for children with ADD and children with CF.

The match or mismatch of environmental press on maternal perceptions and competence parallels theories of normalization. Normalization is the process of constructing a cognitive perception of life with a chronic condition as "just like any other family." In CF the social press supports the development of normalization. ADD presents a mismatch between child behaviors and social press. The press from the community is for a controlled and socially successful child. The press from the child successfully disarms the mother of tools to respond to child behavior. The ADD children do not respond like typical children to spanking, threats, and ordinary discipline measures. Unsuccessful in developing strategies for normalization, many of the ADD mothers opt for social isolation.

Theory Grounding this Research

This research was not designed to test any specific theory. The intent of this study was to describe the subjective experience of mothers dealing with chronic childhood experiences. The theories described, specifically RMFSA, the sick role, and MOHO, were considered in the design of this study and in the development of the interview format. This was done to ensure that the interview

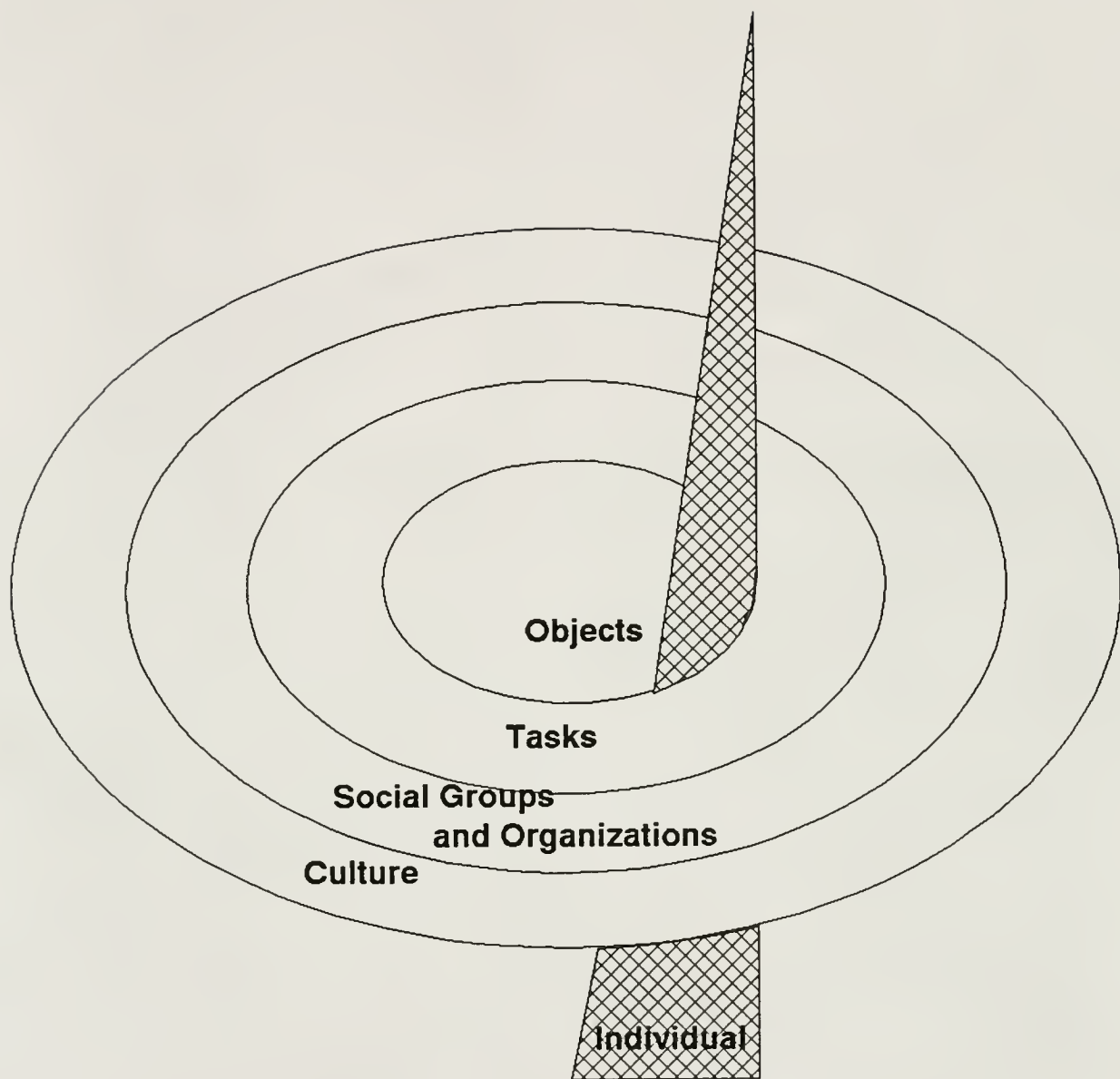


Figure 3 Environmental Influences from MOHO

contained relevant information and could be considered in context with other published research.

The extension of existing theory was considered, but the organization of the theories guiding this research is very different. MOHO is a hierarchical theory in which "layers" are expected to build upon each other in a predictable, orderly fashion. RMFSA is a pattern theory. In the RMFSA the constructs are arranged horizontally and the factors composing the theory are assumed to interact. The way that the basic ideas about the role of routines, roles, and environmental press from MOHO were incorporated is presented in *Table 1*.

Table 1 Integration of MOHO and RMFSA Constructs

Objects and Tasks:	Social groups & Organizations:	Culture:
Pile-up of Demands	Family Support & Priorities	Personal Values, Faith & Expectations
Demands and Routines	Friend Support & Acceptance	Community Values and Expectations
Tangible Resources	Community Support & Resources	Social Values and Expectations

The RMFSA constructs pictured in *Figure 2* and the MOHO constructs included in *Table 1* provided the framework for the development of interview questions and transcript coding. The interview question coding is presented in *Appendix A*. These codes were used throughout the

transcripts to identify comments relating to theory elements.

THE COLLECTION AND ORDERING OF DATA

Grounded Theory and Analytic Induction

This study uses a grounded theory approach to examine the ways in which mothers of children with chronic illness perceive their roles and adapt to family and community pressures. Grounded theory approaches to qualitative research involves systematically interweaving data, abstractions from the data, previous research and theory (Strauss & Corbin, 1990; Glaser & Strauss, 1967; Gilgun, 1992; Charmaz, 1990).

Incorporating the procedures of analytic induction into the grounded theory approach enhances the construction of theory that is grounded both empirically and conceptually (Gilgun, 1992). Classically grounded theory research is done in an open-ended way, without the preconceptions of existing theory. Grounded theory is grounded in the data, which are in turn grounded in time and place. Analytic induction begins with a set of hypotheses and involves matching patterns in the data with expected patterns in the

hypothesis. This adds credibility to open-ended data collection. In this way the type of data needed is collected to compare with existing theory but the data are not led by structured or forced choice questions. Key aspects of the RMFSA and MOHO were incorporated into the interview outline to organize data collection. Within this context I intended to generate concepts grounded in data that may have relevance to existing research. The data were not forced into specific theory aspects. Where they were consistent, they were so coded. Emergent themes were also coded, and some passages were cross coded in more than one manner. I collected, coded, and analyzed the data simultaneously.

Rationale and Specific Aims

The purposes of this research are to describe the relationship of the childhood conditions Attention Deficit Disorder (ADD) and Cystic Fibrosis (CF) with mothers' reports of personal and family stress. The perception of mothers is expected to influence the whole family and reflect both the environmental press and external stressors experienced by family members.

Family variables that are expected to influence the perception of stress include family structure, family demands, and life-cycle stage of the children. These

variables are assumed to behave consistently across disability types. For example, a family with only one adult caretaker is expected to perceive more stress than a family with two resident adults. Families with preschool children and adolescents are expected to perceive more stress, regardless of any chronic illness in the family.

Family vulnerability is a composite reflecting the cumulation of perceived stressors and disability characteristics. High perception of demands corresponds with high vulnerability to stress and family dysfunction. Resiliency, the ability to respond positively to stress and environmental press is seen in family time use, routines, and perceived community and family resources.

Sampling

Subjects for this study were recruited from the J.H. Miller Health Science Center pediatric pulmonary clinics (CF mothers) and the Morris Center (ADD mothers). The regional chapters of Ch.A.D.D., a support group for families with ADD, and CF-Sharp, a support group for families with CF also supplied subjects. To be included, a woman needed to be over 18 years of age, be fluent in English, and have a child between the ages of 5 and 18 diagnosed with either CF or ADD. "Mother" includes biological, adopted, foster, and step mothers. Mothers were excluded if they (or the health

care team) report acute life threatening illness in the immediate family. The researcher visited the clinics and the support groups, introduced herself and briefly described the study. Eligible mothers were invited to participate. Consenting subjects were interviewed during the child's clinic visit, or interviews were scheduled for a later date.

Three ADD mothers and one CF mother who were asked to participate in the study declined to do so. These mothers cited personal time constraints. Seven CF mothers and one ADD mother scheduled interviews and then failed to appear or to reschedule. A total of 44 subjects were included in the study. Each subject consented to the audiotaping of the interview. Data consists of transcripts of all audiotapes and written notes collected by the researcher during the interview.

Table 2 includes basic demographic comparisons of the two subject groups. The area in which the two groups differ most importantly is income. The discrepancy in incomes in the two groups is explained by several factors. Forty per cent of the ADD sample was referred through a private clinic specializing in ADD treatment. To be accepted into this clinic families must have insurance and the ability to pay for additional tutoring and language services. This clinic is not easily accessible to low income or indigent families. Additionally, CF families must have either very low incomes

or very high incomes to assure full medical coverage for their child. Several CF mothers reported that they were afraid to earn much because their child would lose their state medical benefits.

Table 2 Demographic Summary

	CHILDREN	PARENT STATUS*	MOTHER'S MEAN AGE	EMPLOYED^	MEAN INCOME
CF	Mean # children in home: 2.00 Mean # CF children: 1.00 STD: 1.00	Resident Spouse: N= 19 of a total of 22	37.30 STD: 6.53	N = 11 50% Mean: 0.48 STD: 0.49	Mean: 37,957 STD: 38,241
	Mean Age: 11.00 (of CF child) STD: 4.58	86%			Median: \$30,000
ADD	Mean # children in home: 2.32 Mean # ADD children: 1.32 STD: 0.57	Resident Spouse: N= 18 of a total of 21	41.00 STD: 6.10	N = 13 62% Mean: 0.59 STD: 0.43	Mean: 65,636 STD: 43,236
	Mean Age ADD child: 9.69 STD: 3.01	86%			Median: \$42,000

* The family that contains one child with CF and one with ADDH is not counted in either sample on this table
^35 hours a week or more was coded 1 for full time employment. Paid employment less than 35 hours a week was coded 0.5.

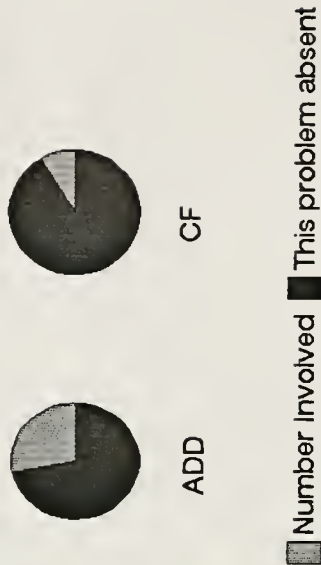
A distinction not clear in this table is the number of impaired children in the home. Only one CF family had more than one child with CF. Nine of the ADD families had two or more children with ADD. One interview subject had one child with CF and one child with ADDH. This interview was not included in the sample summary in Table 2. Figure 4 presents a comparison of some of the important differences

Comparison of Sample Characteristics

Hyperactive/Fragile ADD and CF children



Child mental health problems ADD and CF children



Adopted vs. Biological ADD and CF children



Parent Mental Health Problems (including ADD) for ADD and CF Parents

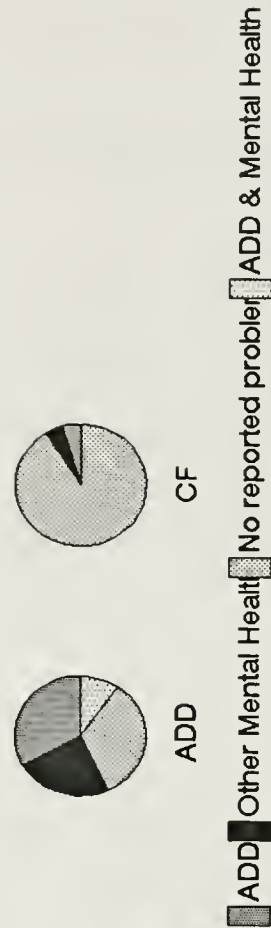


Figure 4 Characteristics of the ADD and CF Sample Compared

in the two sample groups. Specific information about these samples can be found in the following two tables.

Table 3 ADD Sample Summary

CHILD CHARACTERISTICS N= 32				PARENT CHARACTERISTICS N= 22		
	ADDH	Mental Health ?	Adopted	ADD	Mental Health ?*	Resident Spouse
SUM:	25	9	12	8	7	18
MEAN:	0.81	0.30	0.36	0.36	0.29	0.82
STD:	0.40	0.46	0.49	0.49	0.46	0.40
%:	78%	28%	38%	36%	32%	82%

* When a parent is reported as abusing a child, that parent was included as having a mental health problem.

Table 3 presents child and parent characteristics of the ADD sample. ADDH is expected to be more stressful for mothers because the child's behavior is more likely to be disruptive and antisocial. Seventy eight per cent of the ADD children had hyperactivity. This is consistent with the reported incidence of ADDH in the ADD population.

The high percentage of ADD children that is adopted was an unexpected finding. Only one of the adoptive parents in the ADD sample knowingly adopted a child with a chronic condition. For the others the ADD turned up later. It is probable that adoptive and biological mothers will have different personal expectations and different social environments. For this reason, the ADD sample will be considered both as a whole and as two distinct sub-groups.

Counseling for mental health problems was reported in 28% of the children. Four mothers volunteered that they

were being treated for depression. On Table 3 maternal depression and counseling surrounding incidents of child abuse was included in the parent mental health figures.

Mental health problems are likely to be under-reported in both CF and ADD groups because no interview questions specifically targeted this. Studies suggest that child abuse, adult depression, and substance abuse are often seen in families with ADD (Barkley et al., 1992; Biederman et al., 1992). This may account for the difference in incidence of mental health problems seen between the ADD and the CF groups in this study.

Table 4 CF Sample Summary

CHILD CHARACTERISTICS N= 23				PARENT CHARACTERISTICS N= 22		
	Fragile	Mental Health ?	Adopted	ADD	Mental Health ?	Resident spouse
SUM:	N = 6	N = 2	N = 2	N = 1	N = 1	N = 19
MEAN:	0.27	0.08	0.08	0.05	0.05	0.83
STD:	1.28	0.28	0.28	0.29	0.29	0.39
%:	26%	9%	9%	5%	5%	86%

Table 4 presents the characteristics of the CF children and their parents. The children with CF are more likely to be perceived as healthy and few were reported as receiving counseling or psychiatric care. Some emotional problems were mentioned in the interviews, but these were generally in the older children and were focused on coping with a terminal medical condition. Only two of the 23 children

with CF were adopted and both of these children were adopted with full knowledge of their medical condition.

As noted, one mother had a child with CF and a child with ADDH. This mother said that she also had ADD. No other CF mothers reported an adult with ADD or depression in the family. As with depression in the ADD group, there was no specific question to draw this out, and it may be under-reported. With CF there were more marital separations, including one father in prison, and two who were employed in other states.

Child mental health problems were noted whenever the mother reported that the child was, or had at some time attended counseling. This usually came up in the discussion of special therapies the child received, and occurred more frequently with the ADDH children. Since social work is a routine part of CF clinic, it is possible that CF families did not see social work counseling as a distinct intervention. This would result in under-reporting the emotional needs of their children. In both groups the need for mental health support increased with the age of the child.

Instrumentation

An interview using open-ended questions was developed. The development was guided by the theories previously

discussed and organized in *Appendix A*. Four pre-trials of the interview using mothers of children with ADD and other disabilities resulted some additional format changes to clarify questions. The first four interviews were conducted on CF mothers. The issues of terminal disease, frequent child hospitalizations, and normalization required some additions to the interview. Also added to the end of the interview was the question "If I were trying to describe what it feels like living with [ADD/CF] . . . is there something I haven't asked you that you think is important?" No other substantive changes were made to the interview during the data collection period.

Additional notations were kept on whether or not the child was present in the interview, mother's overall outlook, interviewer's perception of mother's affect, whether the disabled child was adopted, referral source, and place of the interview. Two CF interviews were incomplete and the mother of one child with CF had kept her child out of school was unable to respond to the questions about school. To compensate for this an additional CF interview was completed.

Analysis during Data Collection

Open Coding

As the interviews were transcribed, theory references were coded in to aid analysis. Some questions were extended and elaborated on in future interviews to provide additional opportunities for comment on theory related topics.

Appendix B includes the list of codes embedded into the transcripts at this stage.

Labeling Factual Data

Several of the interview questions gathered simple demographic and biographical information. Highlighted in each transcript was the following information about the disabled child: ADD (suspected but not treated), health insurance type, educational placement, interventions (past and present), medication schedule, birth order, disability characteristics, and incidents of child violence, neglect or abuse.

Factual information collected about the mothers included: age, total number of children, health insurance, employment, child care problems, family income, marital status, whether child was adopted, and description of any other family member's disability.

Themes and Issues

As noted earlier, normalization and concerns about the terminal nature of CF were prevalent early themes. Although few normalization behaviors were evident in the ADD sample mothers, the high value placed on it supports its importance in positive adjustment. In ADD the observation that family patterns of adopted and biological children were different led to the extension of interview questions to to expound on these issues. As additional themes occurred they were noted and added to the list of codes to be embedded in transcripts. Transcripts coded prior to the identification of the theme were reviewed and new codes added as indicated. An example of this was the stress associated with having adolescents in the house. In both CF and ADD families, the age of the child related to the stress reported by the mothers. Disabled adolescents in both groups were critical of and inconsistent in their medical regimes. In both cases the concern for the child's future, their dependency on the mother for routine daily activities, and their irreverent views of the medical regimen were sources of stress and family conflict.

Non-disabled adolescent siblings were more likely to express discontent with the attention paid the disabled sibling in both groups. Adolescent siblings of children with ADD were more likely complain of embarrassment and be

openly hostile to the disabled child. For this reason the presence of adolescents in the home was considered a family strain and coded as such.

Drawing Conclusions

Counting. Facts, themes and patterns either predicted by the theory grounding or observed during data collection were noted and the frequency of occurrences tabulated. This allows for verification of the presence of patterns perceived by the researcher. For example, a number of subjects mentioned concerns about their child's future. By looking at the frequency with which these comments actually occurred, and the age of the child to which they were attributed, the relationship between concerns and child's age can be verified.

Gofer (1989) software was used to aid in both counting and categorizing tasks. Gofer is a RAM resident software utility for searching, finding, and retrieving text. This program uses Boolean Logic (and, or, not, nearby) to identify specific text fields and relationships between text fields. This software can search a number of files simultaneously, adding consistency to the data analysis. This method can be used to tabulate prevalence as well as coded themes.

Categorizing. Extending the example above, after determining the frequency of comments coded "concern for child's future," the analyst reads each comment coded in this way. By clustering comments with similar contents trends or changes in content can be identified. This approach will help identify relationships between variables. For example, increasing concern that a child will not be responsible for managing his or her medical interventions was noted throughout adolescence in both groups. While overall comments of "concern for child's future" may not increase with the child's age, the type of concerns reported do change.

The family hardiness and coherence constructs of the RMFSA were originally to be measured by having subjects complete the scales developed for this model after completing the interview. Many mothers reacted negatively to the scales, finding them negative, prescriptive and sometimes ambiguous. Items like "Being active and learning new things are encouraged" (McCubbin, McCubbin, & Thompson, 1986) and "Having faith in God" (McCubbin, Larsen, & Olson, 1982) clearly have socially correct answers. Rather than using these scales, the constructs of hardiness and coherence were considered in the analysis through references to faith, positive and negative outlook, and the mother's sense of personal control.

Axial Coding. Axial coding is "a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories" (Strauss & Corbin, 1990, p. 96). The focus of this procedure is on specifying an observation in terms of the conditions prefacing it. This involves identification of the context, action/interactional strategies, and consequences of those strategies. This puts the earlier coding in a relational form.

For this analysis, data categories were selected that correspond with the theories described earlier. Summary information from interviews was put in table form. Information specific to the RMFSA includes: resources (health insurance and income), family structure, adult's employment status, demands (stresses and strains as defined in RMFSA), school issues, mood, and social network. Looking at normalization and occupational behavior, additional summary information is: mom managed interventions, child demands, social perception of child, child age at diagnosis, child's medical/psychological regime.

A table was generated for each interview and patterns in the data were analyzed by hand. If the summary data were unclear, the original transcript was referenced. Patterns predicted by the RMFSA were considered specifically. The other research issues were sorted in a number of ways in

order to determine relationships between the data and theory, and between the theories.

Validity and Reliability Issues

Reliability of Interviews

With open ended questions and a single interviewer it is difficult to ensure that each subject understands the question in the same way and that there is no ambiguity in scoring. To maximize reliability, this interview was pre-tested in four pre-trial interviews. With each interview the questions were clarified and cues added to the interview form to elicit the specific type of information required.

As noted earlier some of the issues associated with terminal disease were not well developed in the first few CF interviews. This was improved by the addition of two questions: (1) *If I were trying to describe what it feels like living with this disease/disability, is there something I haven't asked you that you think is important for me to consider?*, (2) *Do you have concerns for your special child, like college or future, that you do not have (or think you would have) for a child without [ADD/CF]?*

While no other substantive changes were made some questions were extended. For example the question "Can you think of specific ways that your child's disability has

affected your family in terms of: finances, relationship problems, siblings, communication (with whom?), violence - actual and threatened, available time, vacations/social outings, child care, and extended family?" Was expanded to the following:

"Can you think of specific ways that your child's disability has affected your family in terms of:

Finances?

Impact on marital/romantic relationships ?

Sibling relationships ?

Communication with spouse or significant other ?

Communication with [ADD/CF] child/ siblings?

Violence - actual and threatened

Spousal

Sibling

Vacations/social outings?

Child care?

Extended Family?

Most mothers feel that there isn't enough time in the day. What things do you feel that you don't have enough time for?

Five interviews were transcribed by the researcher, and the entire 45 were transcribed by a professional transcriptionist. There were no inconsistencies between the interviews transcribed by both the researcher and the transcriptionist. At some points the audio tapes were unclear. At these points the transcript is marked [inaudible]. After transcription, the researcher went through the text and added comments from the interview notes. Comments were added in capital letters and/or enclosed in brackets to assure their distinction in the interview text.

Some interview transcripts, in their pre-coded form were circulated to Cindy Capen, RN, MSN (CF specialist), Kathy Noffsinger, RN, PNP (ADD specialist), and Connie Shehan, Ph.D. (dissertation supervisor) for review. Coding strategies were discussed with each of these persons prior to analysis of themes and patterns in the text.

Triangulating Data

In addition to collecting interview notes and audiotapes from 45 individuals, a careful literature review was conducted to identify special themes or concerns common to the two disability groups considered. As trends were observed they were noted by the researcher. Noted trends were compared to the literature and discussed with clinical specialists for ADD and CF.

Trends in field notes were analyzed in the transcript data to determine the frequency and context with which that topic was mentioned. When a trend appeared consistent in the transcripts, the researcher used future interviews to confirm or refute the perceived pattern of responses. Following initial analysis of data for trends and overall content two interview subjects from each disability category were given the summary information and data analysis for content validation.

Emergent Themes

In reading and reviewing the transcripts, some patterns were noted in the data that were not anticipated. If a subject, or specific type of comment came up four or more times it was listed and counted in the research notes. Examples of patterns identified from these notes include the difference in sibling interactions in the two sample groups, and changing parental expectations for the child's future in adolescence. Themes that were worthy of note, but not specific to the research pupose follow.

Medications and social perception in ADD

In describing the social reaction to their child with ADD many mothers offer long narratives, suggesting a complex child-social interaction. For example:

Do you think your child stands out in social situations? On or Off Ritalin? Off Ritalin, Yes. His impulsive behavior always makes him stand out. He is always into something. Always the center of every conflict on the playground. He can be very aggressive in an impulsive way. He is not a mean child, he does these things without bad feelings. The other kids and parents don't understand. On Ritalin, he gets very involved in things. He loves nature, and studies things like insects and rocks. He is very charming and interested with the medicine [AD-13].

How do you think people perceive your kids ? Like in the grocery store? One's going this way, and one's going that way, and I'm going, "come back here, this is one, get here now, hold on to that cart and don't move." Probably that their mother is a total basket case. Does that sound pretty normal? [AD-06]

Social responses of mothers with ADD children divide into those people who had experience with stimulant medication and those who did not. Of the kids with ADD in this sample, only two families (three children) chose not to use some type of stimulant medication. These mothers had never tried medication refusing it based on their beliefs. Concerns about the medicine were that it was a crutch, or an indication of weak character:

[Ritalin] has been talked about, but I wouldn't put her on Ritalin. I don't feel that she's old enough. There's different theories with it. I would rather see her be taught how to overcome her deficits than to put in a crutch in there. An ADD child, you know, has a degree of hyperactivity with some of them. And if this is the case, she needs to learn what her system's going to do. So that she can overcome it. If she doesn't ever learn that, she'll never overcome it. Ritalin at this point in her life, as a six year old, I feel would mask. There's different theories and opinions on it. That's my theory and my opinion. I feel that it would mask what we're trying to do, which is to make her an individual within her own right . . . she needs to learn how to calm herself down. [AD-07]

Mothers, who have experienced their children both on and off medication are often very positive about stimulant medications. Many of the mothers using medications were doing so after fighting their own beliefs against medication:

Have decisions about the use of medications or medical therapies been a source of family conflict? It was a source of conflict and I tried to do all the things I thought I could handle to try. I took her to an allergist. She got needles stuck in her little back to find out everything she was allergic to. She was put on this diet. We tried all kinds of stuff. Well, if she was diabetic we hesitate to give her medicine. She's not diabetic, but if her brain needs this just give it to her.[AD-12]

Social censure is reported by many mothers, but they defend with a medical explanation:

Has the use of medications been a controversy or concern? At first it was, until I saw my neighbor up the street medicate her ADD [child]. So she went through the fights with her husband and all the tears and as we stood back and watched them fight and have tears, and then they decided on medication, and we all saw the results, so we didn't have to go through that. That's the truth, boy. It was great. And for the record, people knock Ritalin left, right and center. Pick up books and you read articles, you listen to your professionals, and call up your drug company and you get the up to date information. And it's not the terrible thing. You treat epileptics, is what K-. said, and I thought that was a very good comparison. No one would hesitate to do that. But they say over and over that Ritalin leaves the body and has been more tested than any other drugs you would give a child . . . So, no, I feel it's the best decision we ever made. And the other thing is, when you see your child going through such distress and they're coming and they're crying, it's merciless not to do something about it. I mean they're really in bad straits.[AD-19]

Have decisions about the use of medications or medical therapies been a source of family conflict? No. We talked about it for a while and looked into other options. But the difference it makes in him is so dramatic that it was an easy decision. Other people are really negative about Ritalin. We just don't talk about it. We don't let people know he is taking it unless they need to deal with it. [AD-01]

Some ADD parents develop rather sophisticated defenses to this type of social sanction.

And here in [city], you have group conferences. You have seven teachers. And the parents sit there, and they go, da, da, da da da, this is happening in my class, and this is the way he's reacting and so forth. And [my husband with ADD] went to one . . . and I'll never forget it . . . I had [the child's] psych report there. And it says in the psych report that organizational skills and motor skills, fine motor skills, like handwriting, are very difficult. They're nonexistent. And they were complaining about his handwriting, and he couldn't organize, and he was losing things,

and couldn't get something turned in, and I said, "Well, if you'll turn to page three, paragraph three of the psych report, and you look at what he says right there. I mean, this is what you're talking about. The child neurologically cannot do what you're asking him to do." And they're looking at me like, "Yeah, mom, you're making all these excuses." And [my husband] said, "I'm here to tell you I'm an adult and I have the same thing this child has. I have a four year college degree. I have a very successful career. But in the last five minutes that we've been in this classroom, you crossed your legs, you dropped your pencil," he went all the way down the line telling these people what they did. He said "I hear everything going on in that hall. I hear everything going on inside this room." He said, "My child is just like that." And they had a different attitude. So he can be very effective. [AD-05]

Other mothers are less confident in medical explanations, and more likely to be critical of either themselves or their child. Both self-criticism and criticism of the child occur in the following ADD mother's account.

Did knowing what was going on provide a stress or a relief? It was a relief to know there was a name for it, that he wasn't just mean or a bad person. How do you think people perceive your special child? As being unruly, dominant. They think he's a bad influence, probably. This is my child I'm talking about. It's horrible to think about how he is. When you meet people socially with your child, do you usually tell them about the problem? No, I enjoy telling people. Because I don't want to people to say, "Look at that mother, she can't handle her child." I don't enjoy it. That's not the right word to say. But I want people to know that he has a problem, it's not just that he's bad. Because he's not bad. You know, I don't want them to think he's bad, like everybody does. I want them to know there's a reason for it. I mean, I don't walk around and tell everybody, but the people I'm close to. Put a banner on the house. [AD-02]

Challenges to Mother's sense of well-being in ADD

There is abundant evidence in the literature that with ADD, there are often other family members with mental health problems (Barkley et al., 1992). Mothers of ADHD children reported higher depression scores and higher alcohol consumption than the mothers of normal children did in the study by Cunningham, Benness, and Slater (1988).

There were no interview questions specifically relating to parental mental health or alcoholism. In spite of this there was a clear pattern of ADD mothers who were medicated for depression, and even more who were negative and depressed in their affect. Several instances of actual child abuse within the families were recounted. Even in those families that appeared to be managing well, comments like:

Well, I can get, you know. I'm not proud of it. No one ever called HRS. I remember, though, bless her heart. I was [involved in a support group] and there was a lady who came in, someone did call HRS on her. She was hitting the kid in the car and somebody drove by and got her license plate number and what a mess, you know. [AD-14]

Although ADD mothers did not report more health problems, they did consistently list physical and emotional exhaustion. The most trying time for most mothers seemed to be the late preschool years when "the terrible two's never ended." Quite subjectively, the researcher perceived a greater dissatisfaction with their marriages than the CF

group. The only divorces or separations discussed in the CF group that were attributed in some part to child stresses were in families with a suspected ADD child. In that case the ADD behavior was singled out as the problem. In the ADD group each reported divorce was believed to be influenced by ADD's demands on the family. In both groups there were a couple of re-marriages, where the mother was now married but a divorce was attributed in some part to the child. Past divorces or separations were not considered in this analysis. No attempt to lend tangible support to this theme was successful. In attempting to count mentions of their spouse in the interview and mentions of the spouse as a support on the social network list no clear pattern emerged.

ADD and the Health Care System

Not reported in this paper are a number of involved stories in response to "Tell me the story leading up to your child being diagnosed with ADD." Not only did ADD parents consistently get told that their child would grow out of it, or that it wouldn't be a problem if they were more consistent with discipline, but many spent one to five years, usually beginning when the child was about four, going from physician to psychologist to psychiatrist to neurologist and so on before finally having someone affirm that their child was atypical and that the problem was not

exclusively poor parenting. During the lengthy search for an explanation for their child's unusual behavior, two mothers reported incidents of child abuse and several children were held back in school.

ADD is a disputed, and perhaps excessively used diagnosis, but the medical literature affirms its existence. The hesitation of primary care providers to refer for testing, to routinely screen, or at least to screen at the parents request is not explained. Mothers reported difficulty getting their health insurance to pay for ADD interventions. Is the lack of action on the part of primary care persons a lack of knowledge, or a concern about reimbursement?

One explanation for lack of testing in the public school systems was offered by a school system employee with an ADD child:

When a mother asks me about that, I tell them that I don't mind the label for the future, because when my kids get to be college age, they're going to need the tutor, they're going to need the smaller classrooms, they're going to need the oral tests to get through college. And that's where that label is going to come in handy. That's where I'm going to use that label more than anything. And I've had public school people tell me, "But don't you know, if you tell a mother that the kid's ADDH, that means that they will get \$300 a month in SSI. Is that where you want your tax money going?" [AD-06]

This topic clearly warrants further research.

Perception of Antagonism by the Health Care Establishment

In both samples there were a few families that seemed very marginal in both their attitudes toward intervention and the stand they took to advocate for their child. The following excerpt from the data presents a mother's social construction of her family at odds with the health care system:

They do not seem to try to understand G.'s . . . problem. G. had major sinus problems when he was starting school when he was five and a half, six. They found polyps growing out of his nose . . . and come to find out G.'s sinuses were totally blocked all through his head even in back of his eye . . . So they went in and microscopically laser went in and opened up all of those drains and put new drains in his face going from each sinus over and also down through his lips . . . And G. doesn't, **they won't believe me**, G. doesn't smell very well . . . And of course in that sense, he doesn't taste very well. So he just hasn't got an appetite. **That's just the way it is. And they have seemed to want to blame that on a psychological problem.** . . . they've never tested his taste, they've never tested his sense of smell and tried to relate that . . . They've tried motivation, they've bribed him, they've given him money to eat, which is against how I believe, you know, and I've asked them to try a gastric tube. [CF-21]

Up until this point we have a mother recounting the history of her son's eating problem. Clearly, she believes that the problem is biologic and that the best answer is to just tube feed him. Tube feeding a 14 year old is considered a drastic measure by medical providers, especially in the case of a perfectly functional child. This family was both non-supportive and non-compliant with health care recommendations on the basis of their beliefs.

While the health care team was presenting the gastric tube as a negative outcome, the mother responds:

I talked to him about it. And I told him all I knew about a gastric tube and how good it was . . . and I explained what a button looks like, not a big operation, and not a big deal, and there's a lot of kids who have gotten past this stage and grown well and realize how good it was, and got out of it, whether it was psychological or what it was. So two years ago, we went for two months with him passing the tube every night down his throat . . . after two months of doing this, he'd gained six pounds. So obviously it would work. And they promised him in January they'd put it in. Then in February they didn't, in March they didn't, in April they changed doctors . . . He had gone in in April to have it put in and they weren't going to do it. Now, I've had problems there, because they made this child a promise and they built him up that they would work with him if he did what they asked him to do. Now they don't even want to talk about it . . . To me, they're not dealing with the problem. The doctor thinks I have a problem and I'm doing something awful to my son. I mean, he's told me that . . . I feel like they've let him down. And they are making me out to be the evil one for trying to force a tube in my child. And that's so far from the truth . . . You want the best for your kids. And sometimes you have to fight your way through the health care system.[AD-21]

It appears that this mother as "parent advocate" actively defied the strategy of the medical establishment. She is hostile and angry with talk about broken promises and lack of sensitivity to her child. In terms of her family "collective consciousness," the family beliefs are challenged. Clearly, regardless of whose side is taken, the child is being poorly served.

In another instance, the frustration is with red tape. In this story the results of professional inattention were catastrophic.

We were consistently told that [he'll] outgrow it. He had a wonderful kindergarten experience. The teacher suggested that he be tested for a learning disability and gifted program. The paperwork got lost. First grade came, the teacher said, "Oh, he's just a little behind." By the end of the year, now this is going in and telling them the history, that we know that this is a problem, "Don't worry about it, he'll outgrow it. He'll catch up. Boys are always a little behind." At the end of first grade, by March of first grade, we need to have him tested. Second grade they had not done any of the testing and then the new psychologist at the school who didn't know anything about any of the things that were supposed to have been done before and there was no paperwork. Second grade teacher said, "I don't believe in learning disabilities. He's just lazy and is not paying attention." By November, no October, K-. was refusing to go to school, crying, just depressed, miserable, unhappy. I went in and explained to them that they had until December 31 to complete the testing or I was going to sue them one and all. They got the testing done. K-. was diagnosed as learning disabled with auditory and visual processing deficits . . . We met with the classroom teacher, the school psychologist, the district psychologist, went over the test results, and the teacher said, "But if he would just pay attention, he could do it." We had to move him to a different classroom. He went into special ed an hour a day. And his confidence went up, skills improved, no more depression, just did beautifully. He went through summer school. The principal refused special placement on K-.'s needs. He went into a [regular] classroom. The first thing the teacher said was "K-. doesn't pay attention. He's a daydreamer." You know, "He's just not paying attention." K-. ended up hiding instead of getting on the school bus. He would hide under the culvert and stay there all day, under the road instead of going to school. Nightmares, extreme depression. We met with the teacher over and over. We met with the principal and suggested that he be moved to a different class. He was flunking all of his regular classes and doing perfectly with no problems at all in his special ed class. The two teachers never spoke to each other. We went to our pediatrician to try and get an evaluation because [the health insurance company] has some additional coverages but they have to be approved. He for whatever reason didn't do it. K-. became extremely depressed. I called the pediatrician and said, "You have to get us a referral; this child is just going to pieces." And he said, "Okay, take him to the emergency room, tell them that he's very depressed and you want a referral for an

evaluation. Because that way [the insurance company] has to respond immediately." Unfortunately, the emergency room doctor decided that K-. needed to be [involuntarily committed] not hospitalized. He was [committed] and sent to [a psychiatric hospital] where he was terrified. We got him out seventy-two hours later and have spent the last three years trying to put the pieces back together. I mean, we could talk about when he came home from the hospital and was a completely different child than before. And then that it took six months for him to be able to feel safe enough to tell us that they had done a sleep deprived EEG and took him in a room and set him up on a wooden chair and strapped him in and hooked all the electrodes to him and because of his auditory processing deficits, he thought he was going to be electrocuted for not going to school . . . I have a certain hostility. Prozac has been helpful. There's a whole world of things that can go wrong that you never would suspect and it's very frustrating. We are now, after three years, and one month, finally being able to deal directly with things that have to do with attention deficit disorder. So it's been somewhat stressful.[AD-03]

Adolescence and Chronic Disability

In both subject groups the focus of mother's concerns changed at around the age 14. At that point the children began to deny their disorder existed, often refusing or balking at medical interventions. This was especially worrisome to CF mothers because adolescence also coincided with an exacerbation in the child's health problems.

A recurrent concern was children assuming responsibility for their own medical care. Several of the mother's interviewed expressed that their CF children did poorly in school, but that no more could be expected of them with their frequent illnesses. With the increasing life

span of children with CF, it is expected that more parents will face the dilemma of this mother of an 18 year old daughter with CF.

I do think that any time you have a worry about an illness with a child, that's got to be a big stress. I mean, it's a given. Just from pure wondering how long you're going to have this kid, whether you can make them capable of taking care of themselves. Because I think the ultimate for any parent is to want your child capable of taking care of themselves. And you have this realization this may not be possible, so how are you going to provide for that when you're not around. And especially with an only child. No siblings. You think, "Okay, who is going to end up with this kid and how is that going to affect their lives." If they do make it, or if I were killed in an accident, that's a worry for me now. Because I'm down here, [her father's] up there and if she's going to be living here, my parents are in their seventies, you know if I were killed, how is that going to work out? So it's things like that. They lay there, but you think, "Okay, what do I do?" And so, I don't know. I mean, you don't really to throw it at another relative. They have their own kids, their own lives, whatever. But you don't want your kids taken care of by the state in some way, shape, or form, and by that time she will be twenty-one and who's going to care? You know, they'll see her as an adult. So the ways the laws are set up to care of adults with this kind of illness, they say, well, she'd have to live on her own in order to collect or be in an apartment. Well, what if she's sicker. Then what? You're telling me I can't take care of her because she's got to live over here and I've got to live over there? So what? I have to rent an apartment in order to make it look good? So it's just added stress and it shouldn't be. And yet it's the way the system's set up. It's not a system that works for you. It works against you. So it just creates more problems.[CF-17]

With ADD, the problems were more typical of the problems faced by other parents of adolescents, only larger. Each ADD parent has heard how much higher the chance is that their ADD child will take illegal drugs, get in trouble with

the law, have an unplanned pregnancy, develop a psychiatric problem or be unemployed.

How did your major concerns about your child seem different when she started to school? Yes. When we started out, we were dreaming of a neurophysicist prima ballerina. And now my goal is get to age 18 with no grandchildren with a high school diploma and no addictions to anything. That's my goal. Very simple.
[AD-04]

As with CF, many of the adolescents with ADD began to refuse medication. In this case it was easier because ADD is not fatal. In late adolescence (from about 16 years) many parents felt a relief from the stresses of parenting. These mothers reported that the child was becoming responsible and in making decisions like refusing medicines would feel the impact of those decisions very directly. Whether the lessening of parental strain is due to the child's maturation or to the parents' ability to step back and say "its out of my hands," unlike typical parents, some ADD parents feel less strain at this age.

Siblings and Chronic Disability

The theme was poorly developed because it was not a consideration in the research question. Sibling interactions illustrate an instance where the ADD and the CF groups divide distinctly. Both groups of mothers occasionally mentioned sibling conflict or jealousy. This conflict was most common in the adolescent years, but in

some cases began quite early in the child's life. In general sibling conflict was both more common and more severe in ADD.

The CF siblings tended to have problems like those described by Mulder and Suurmeijer (1977) for siblings of children with epilepsy. The tension between siblings is believed to be the result of the parents' psychological stress and fear for the impaired child. They report that "mothers, and to a lesser degree fathers, tend to become overprotective. These children are relatively isolated socially, and have lower expectations for the future and curtailed scholastic behavior" (Mulder & Suurmeijer, 1977, p. 13).

The problems of the ADD siblings are more related to the social behavior of both children. ADD behavior is both embarrassing and threatening to siblings. Siblings who stand out negatively in social situations also draw negative attention to the unimpaired sibling.

[The older sibling] is embarrassed by S-. She keeps her friends away from S-. They are sisters, but they are not friends. They may never be . . . the fights are awful. So she and S-. , hopefully by the time they're adults, they'll be friends. But they're not friends now. [AD-12]

The other big source of conflict is that amount of parental time and lowered performance focused on the child with ADD. Several mothers mentioned these problems in their household. While it was a small problem for mothers of

elementary school-aged children, the problem seems to grow through adolescence.

K-. thinks she [gets less attention than she needs]. This is the child that consumes most of the family income with her horses. She still gets jealous of little things I do for S- . . . But if I bring S-. something, I better bring K-. one or maybe both. And now K-. 's 17 and it's very hard, she's the very hardest one. And so K-. needs her fair share of everything. Even though I know that she gets enough love and attention. She's always watching what I do to see what she gets.[AD-12]

When two children are very close in age and one or both have ADD sibling problems abound. In this sample several mothers described siblings picking on each other and siblings being ignored because of the demands of the impaired child.

Do some of the people in your family seem to need more attention than they are getting now? Probably my daughter. She really gets robbed. She needs some more love. Just some more. You get mad at him for something and it carries over to her, and if you weren't irritated with him, you probably wouldn't let whatever little things she does bother you. So she probably loses out.[AD-04]

Because my kids are so different, their relationship is very complex. I'm trying to distinguish where the ADD lets off and just normal siblings, but I think it does. G-. , by root, is able to focus for much longer attention spans than his brother, who's two years older than he is. D-. , when he's in his hyperactive state, will fight with G-. on more G-. 's level, physically, where I think if he wasn't [ADD], and he didn't have that component [hyperactivity], he would just be able to blow it off easier. So I think there are definite impacts.[AD-15]

Have these concerns changed since your child's disability was identified? Sibling kinds of stuff. I mean, when I see siblings that actually get along, it's like, oh wow, what would that be like. Because mine are always fighting. Between R-. 's tactile hypersensitivity, and I mean, she has started her

menstrual cycle, and about five days before, during and five days after, you don't get near her. I mean, between the tactile stuff and all the other raging hormone stuff, you just don't get near her. So her brothers get floored. I mean, they're picking themselves up off the floor . . . one of the reasons why we went ahead with the Ritalin was because of the other kids in the family. One of the reasons why we keep P-. on Ritalin on Saturday and Sunday is because of [younger sibling] and the other kids in the family. Because they get very physical and I think that's probably my biggest concern [AD-06].

Little research has been conducted on the effects of ADD on siblings. This study indicates that sibling relations have a large impact on the mother's perception of personal control, of herself as a mother, and on the sense of well-being in the household. This topic also warrants further study.

Special Issues and Ethical Concerns

Mothers who chose to participate in this research were often quite candid in discussing difficult and intimate thoughts. In order to help participants feel comfortable I met with them wherever they requested. While some mothers were most comfortable at home, others pointedly did not want me in their home. I dressed casually for interviews and tried to maintain an easy conversational style. In some cases the child was present at the interview. In those cases I tried to be sensitive to the parent-child relationship and was less probing with my questions.

I assured all of the mothers that names and identifying information would be altered during the write-up of this research. I also emphatically stated that the only persons to actually hear the transcripts would be myself and the transcriptionist. At any point a mother could refuse to answer a question or avoid a topic. Many subjects seemed uncomfortable with questions about family income. In those cases I explained how the income information was going to be used and assured them of confidentiality.

Some of the mothers expressed concern about my reactions to their responses. They would say "You're not going to like this. . . ." when criticizing their occupational therapy home programs or "I'm really not a bad mother." In all cases I tried to remain positive and encouraging. In all cases I assured them that there were no wrong answers, that the study was about how *they* perceived things, not about other peoples' ideas.

After the initial questions about income, no mother expressed discomfort with my questions. Some were highly self-critical but seemed comfortable with me. If a mother knew I was an occupational therapist and had specific questions relating to that I did answer them. When asked if their comments were similar to other people I generally said "yes." Only in the instance of the CF mother whose child was not eating did I deviate. I hoped to help her establish a mediator between herself and the pulmonary clinic. I

offered her the names of several people at pulmonary clinic who were persistently identified as "wonderful" by subjects in this study.

Several mothers reported a history of actual or suspected child abuse in the home. While this information was included in general terms, none of the specific child abuse stories were included in this paper. Any references to child abuse extracted from the transcripts for this paper have been significantly changed to protect the anonymity of the mother and child.

On a few occasions there were inconsistencies in the mother's stories. One mother introduced a gentleman as her spouse and named him as one of the adults in the home early in the interview, only later to list him as her boyfriend who lives three miles down the road on the social network list. In this and similar cases I recorded the mother as married, because that is how she described herself, and treated the "boyfriend" as spouse on the social network analysis.

In the lower income ranges, especially in the CF groups there was a lot of inconsistency in reporting income. By looking at all the cases receiving public support it was fairly easy to discern SSI disability payments to the family. Using the families who reported exact figures for all sources I established general income figures for the families on public support that was consistent across this

sample. The mean of my estimated figures is higher than the actual figures provided, but is believed to compensate for the vagaries of reporting in this group.

All of the research data were obtained by parent report. I did not cross check or verify any information with the medical records. I took this stand because it was the mother's perception I was looking for. At first I noted the mothers affect in my interview notes, but discontinued this process because I was not confident in either my objectivity or the utility of that information. In fact, I could not help but hear some of the comments of health care providers about how crazy, or non-compliant, or great some mothers were.

Because of my emphasis on mothers report, it was suggested by one of my expert reviewers that ADD children with other psychiatric diagnoses were not accurately represented in the group. She commented that a child with ADDH and conduct disorder would be far more disruptive in the home than a child with ADDH. Only one mother reported conduct disorder when asked if her child had any other diagnoses. Although it was not reported, there were certainly at least a couple of other children with additional mental health diagnoses in the sample. This is an important consideration, especially in my intra-group comparisons of ADD. The differences between the biological families and the adopted families discussed in the next

chapter may be moderated by a consideration of the presence of any other childhood mental health condition.

MAKING AND VALIDATING STATEMENTS OF RELATIONSHIPS

The analysis stage of this research could not be discretely identified. Some analysis took place during the interviews as I made decisions about what topics to pursue and how to structure probes. I made analytic notes to about concerns or issues to consider in later interviews. For example, in many of the early CF interviews the child was present and it was difficult getting past the "we're a happy, normal family" line. Whenever possible later interviews were conducted outside of the child's hearing. The imbedded coding and additional analyses needed to make and validate statements of relationship were completed after the interviewing was complete and the transcripts were available to code. There was a tremendous volume of interview data. There was 600 to 700 pages of interview transcripts and about 10 pages of analytic notes. I assumed theoretical saturation had occurred when the interviews revealed no new concepts or challenges. Data analysis included constant comparison within and across cases. The focus of this chapter is the analysis of data related to existing social theory.

RMFSA Constructs

The adaptation phase of the RMFSA begins at the level of the family's adaptation over time to recover from the "crisis" of chronic disease and/or the family's transition back into a crisis situation. This level of adaptation is brought by the subject to the interview and is treated as exogenous to the interview. Specifically, interview data included both the child's age at diagnosis and the history of the child's diagnosis. The responses to these questions were consistent within each disability group. Most of the children with CF were diagnosed in the first year of life (mean age six months) and the period of dealing with the problem was short and intense. The mean age of diagnosis in the ADD group was six years. The youngest that a child received the ADD label was four, and the latest that any child in the sample was labeled was 15.

Thus, families dealing with CF had had several years prior to this interview to adapt to the problem. Families with ADD had far less time, and in three cases a younger sibling of the ADD child targeted for the interview was diagnosed at or near the time of the interview. For this reason alone, the CF group as a whole is more likely than the ADD group to have normalized the care of their child.

Family Demands

Each subject brings to this research a unique history of stresses. The mother's demands were gathered using the following question:

Have there been any big events in the past couple of years that affected your family like:

- A family member gave birth to or adopted a child.*
- A family member stopped working, lost or quit a job.*
- A family member started or returned to work.*
- Family moved to new home/apartment.*
- A family member, relative or close friend became seriously ill or injured.*

In the analysis no attempt was made to weight the relative severity of the stressors listed. Any demand identified by the mother was coded in the interview. Open-ended questions about perceived demands follow.

Are there additional physical demands on you in dealing with your special child?

Are there additional emotional demands on you in dealing with your special child?

Do you think that dealing with the pressures of having a child with special needs has led to: Increase in conflict or arguments? Increased difficulty with people at work or dissatisfaction with job/career? Increased time spent at home, rather than doing things outside the home?

Can you think of specific ways that [special child] has affected your family: Finances? Marital/romantic relationships? Sibling relationships? Communication with spouse? Vacations/social outings? Child care? Extended Family?

Do you think that dealing with the pressures of having a child with special needs has led to actual and/or threatened violence in the home?

Comments related to any of these specific topics, both general and child related, were coded and counted as demands. Other data coded as demands were: presence of a pre-school child (under five years old), a teen-ager (14 to 18 years old¹) in the home, only one resident adult, mom-managed interventions such as tutoring or IV therapy, sibling conflict, other medical diagnoses of any family member, and a difficult child (ADDH or fragile CF). The distribution of demands is presented in *Figure 5*.

The summary statistics for this data are presented in *Table 5*. Respondent 5 in the CF group is the family with three CF children. Although the general pattern is consistent, the presence of this outlier minimizes the differences between the two sample groups.

Total number of demands were higher in the ADD group. The number of general (non-child related) demands was very similar in the ADD and CF respondents. A greater percentage of general demands should be seen among CF mother's because of their lower family income. The observed difference between the two groups was minimal. This CF population may differ from the general population because for this sample low income is not tied to a lack of health care services for their child.

¹Fourteen was used because it is the youngest age child with which any mother in this sample complained of problems with compliance on their medical regime.

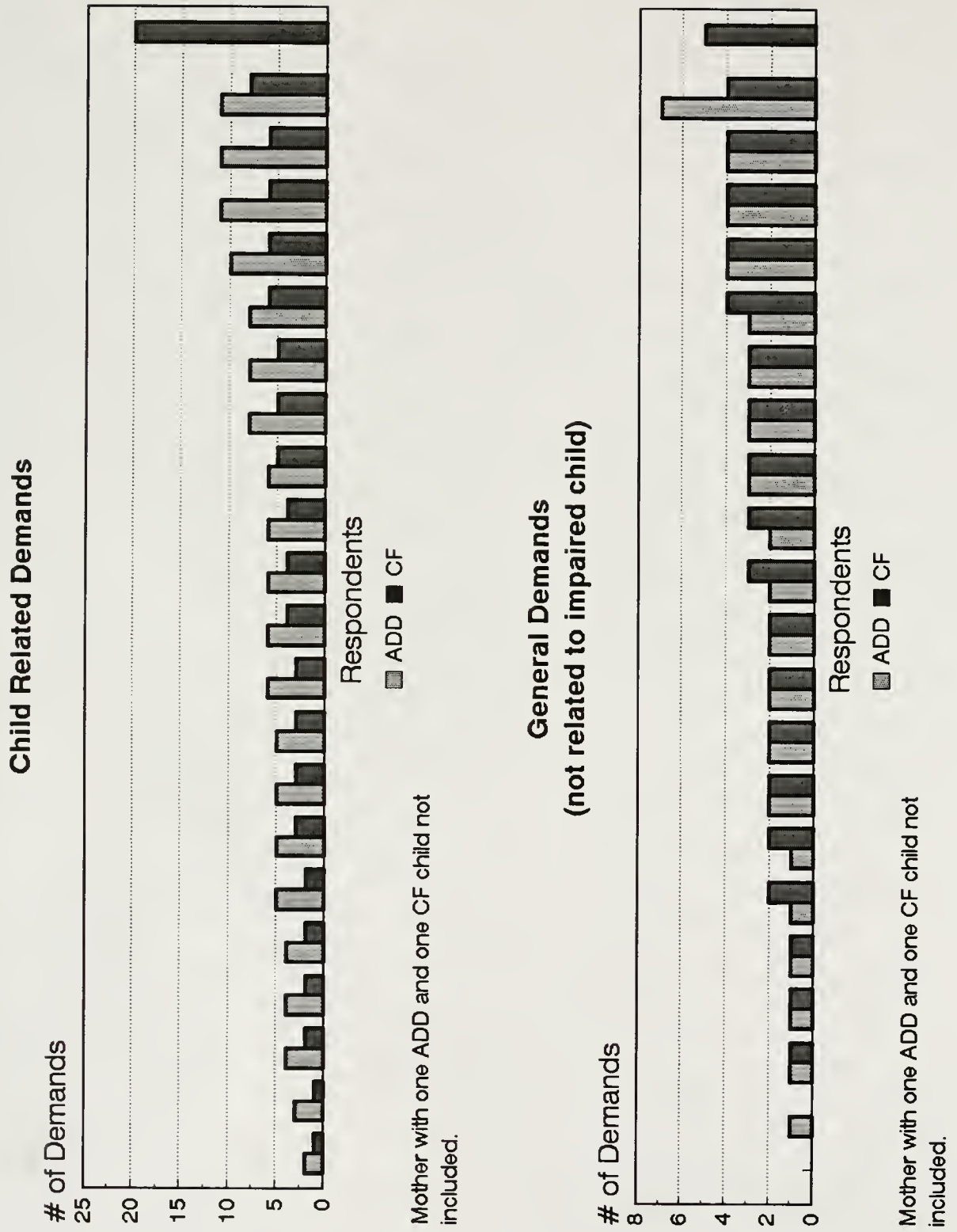


Table 5 Summary of Demands

	General Demands	Child Demands	Total Demands
CF	SUM: 61 MEAN: 2.65 STD: 2.00	Listed Child Demands* Sum:73 Mean:3.17 STD: 2.29	All Listed Demands Sum:134 Mean:5.83 STD:2.66
		CHILD DEMANDS REPORTED ² SUM: 105 MEAN: 4.57 STD: 3.82	ALL DEMANDS REPORTED SUM: 166 MEAN: 7.22 STD: 4.24
		Child Demands Reported & Hospitalization** Sum:137 Mean:5.96 STD:3.60	All Demands reported & Hospitalization** Sum:198 Mean:8.61 STD:3.89
ADD	SUM: 53 MEAN: 2.41 STD: 1.59	CHILD DEMANDS SUM=139 MEAN: 6.32 STD: 2.68	TOTAL DEMANDS SUM=192 MEAN: 8.73 STD: 4.94

* This row lists non-intervention demands named by the respondents

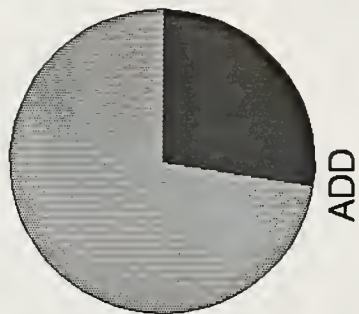
** This row includes all listed demands, therapies, and hospitalizations (hospitalizations are counted as reported or, when there is no report, counted as two per year).

The ADD subjects reported about one and a half more demands than demands reported by the CF subjects. Of the total demands reported by the ADD group, about 72% were specifically attributed to demands of the child (or children) with ADD. ADD families had nearly 9% higher disability specific demands than the CF group. This difference is illustrated in *Figure 6*. The representation of data on demands and social network in *Figure 6* is

²This does not include all likely hospitalizations. This is problematic because it probably under-represents demand. However, only 5 of 23 families actually mentioned hospitalizations when asked about demands. It seemed inappropriate to count those 5 hospitalizations and not the others. It seemed equally inappropriate to add a hospitalization demand to each CF interview. This issue will be discussed further later in the text.

Distribution of Demands

ADD and CF



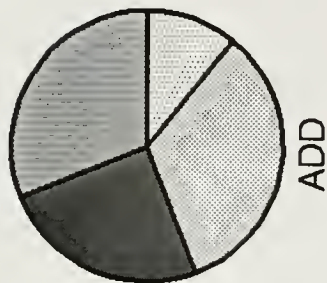
Mean # of
ADD demands 8.73

Mean # of
CF demands 7.22

■ Child Demands ■ Other Demands

Social Network

ADD and CF Mothers



Mean # of
persons in ADD network 4.0

Mean # of
persons in CF network 3.6

■ Family ■ Friend ■ Other ■ Under-reports

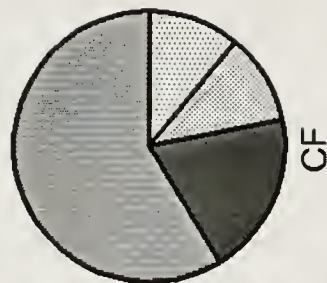


Figure 6 Distribution of Demands and Social Network

consistent with the research finding that "compared to parents with normally developing children, parents with externalizing children reported more negative impact on social life, more negative and less positive feelings about parenting, and higher child-related stress" (Donenberg & Baker, p. 179).

Family Resources

Family resources considered in this study are: the availability of health care reimbursement, family income, and personal support networks.

Income. As presented earlier in Table 2, the mean income for CF families is nearly \$28,000 per year less than the ADD group. The standard deviation in both groups is very large. For this reason the median incomes will be used as a summary statistic in the analysis of family resources. Median income is a better indicator of family resources because it is not influenced by extremes in the sample. Twenty six percent of families in the CF group, including the family with both a CF and an ADD child, rely solely on public support. In the ADD sample, only the family with both a CF and an ADD child relies on public support.

Social-emotional Support. Information about who provides anything perceived by the mother as help or support was obtained at the end of the interview. Any person

mentioned during the interview as helpful was included on the social support list, if they were not already listed. Two of the CF mothers did not complete this part of the interview due to time constraints, these two transcripts will be eliminated from the analysis. The social network list was introduced with the comment:

Please tell me who has been important or helpful to you in dealing with your child's special needs. This may be a family member, a friend, a neighbor, or a professional such as a nurse or minister.

Mothers were not prompted to reply in any particular manner. If a mother asked a specific question about who to include, she was instructed to include anyone who helps her deal with the demands of raising a child with (CF or ADD). Figure 6 presents the distribution of the social network information comparing the ADD to the CF groups. Table 6 summarizes this data. Figure 7 compares the individual responses in each group.

The category "other" includes health professionals, clergy, teachers, and any other individual mentioned who did not fit in other categories. The category "under-estimate" was used whenever a mother listed a large group of people or a non-acquaintance as a support. For example, many CF mothers listed "the whole pulmonary team at Shands." Also common to this category were school systems, and churches.

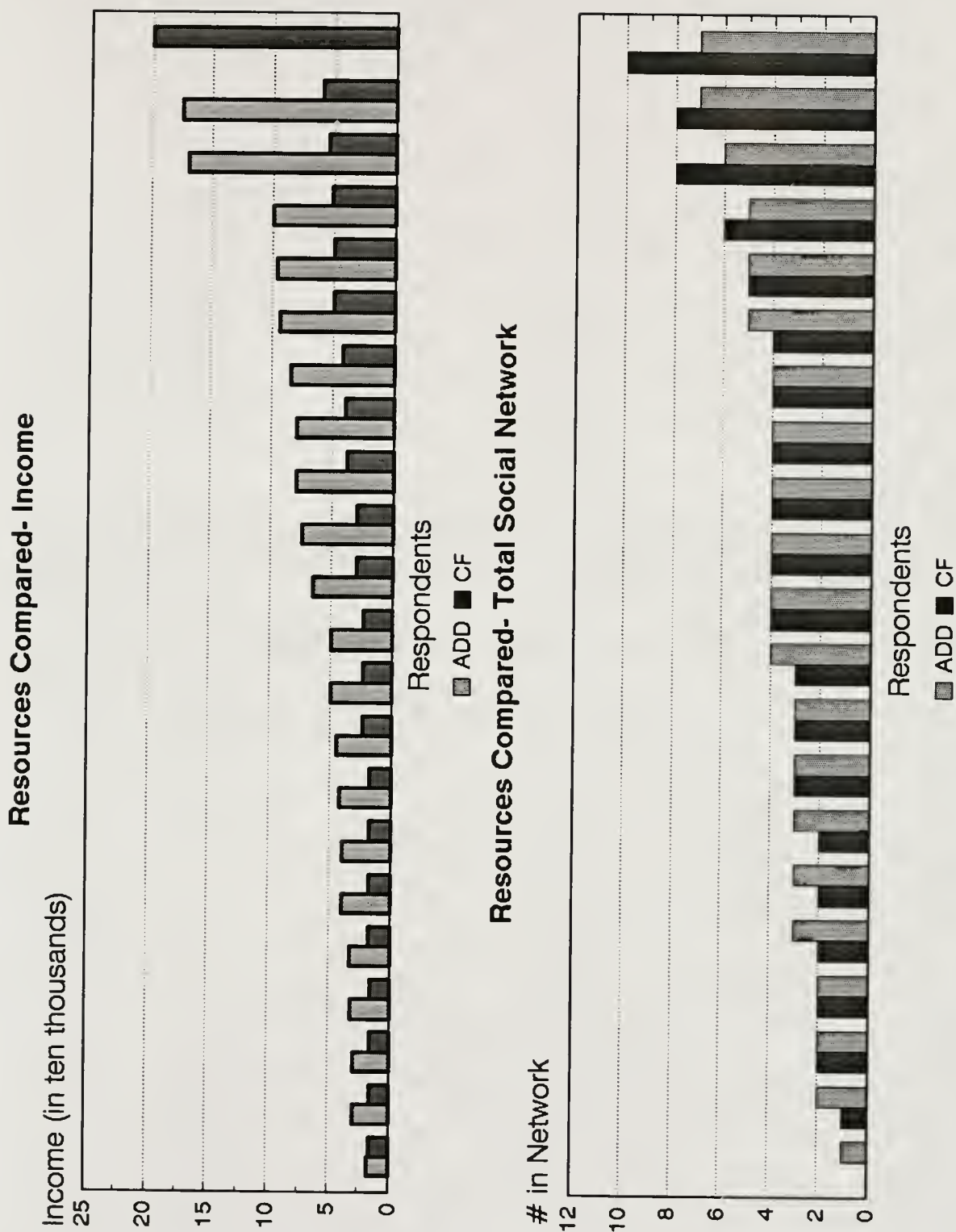


Figure 7 Social Resources in ADD and CF Samples

"Under-estimate" was used to suggest that the method of obtaining measures of support by listing individuals underestimated the mothers' actual perceived support. Non-acquaintances included book authors and internet news support groups.

The total number of social resources is similar in the two groups, with similar mean numbers of helpful persons. While comparable in total numbers of people mentioned, the distribution across types of help is quite different. This was illustrated in the social network chart of *Figure 6*. Mothers of children with CF are much more likely to receive help from family members. Common types of help offered

Table 6 Summary of Social Network

	Spouse*	Family	Friend	Other	Total
CF	47% listed	Mean: 2.19 STD: 1.60	Mean: 0.86 STD: 0.96	Mean: 0.48 STD: 0.87	Mean: 3.6 STD: 2.54
ADD	52% listed	Mean: 0.96 STD: 1.09	Mean: 1.05 STD: 1.00	Mean: 1.41 STD: 0.96	Mean: 3.8 STD: 2.00

* Spousal support was only counted when the subject reported that she was married

include emotional support, child care, and physical assistance. Several examples of the kind of family support received by CF families follow.

Well, when J-.'s in the hospital, they'll do whatever I need to have done. If it's take him something, or pick him up and take him somewhere, they just are always ready to do whatever I need them to. And they're also very emotionally supportive. [CF-01]

She does everything for me. When I didn't have a car, she drove me around. She's there for me emotionally. [CF-02]

Well, basically, anything that he can do. Emotional, financial, physically taken her to school, doctors, or just picked up pills. He's done anything that I would want him to do. More than that he's aware of the problems. He's aware. [CF-05]

We talk every day. She calls every day or I'll call her every day. We've already talked today and she gives me a lot of emotional support that I guess only a mother could do. And tries to keep my spirits up. If he does get sick, and I may have an emotional second there to where I feel like it's all caving in and whatever, you know, is he going to get over it, you know. [CF-10]

High family support is common to studies of family networks in childhood disability (Kazak, 1987; Kazak & Wilcox, 1984; Kazak, 1986). Mothers in the ADD group find far less support from their extended families. Many ADD mothers feel that their families are uncomfortable around their child, and for that reason are not good sources of support.

They love and accept her, but its like . . . well. She's still singled out, the other kids don't play with her. Some people don't understand about the ADD . . . others use it as an excuse. They feel sorry for her and have lowered expectations. Neither of those is very good for S-. [AD-12]

This mother was as positive about her family in general as any of the CF mothers, but her description of family help is far narrower than that commonly described by the CF mothers.

(Re: Sister). Very supportive, understanding, and helpful to me. She'll keep S-. overnight. She understands. She lives here in [town]. [AD-12]

It may be that the needs of the ADD families are less concrete. Frequent hospitalizations of the child with CF offer extended family members some obvious ways to help.

The type of help needed by ADD moms is less easy to define and dispense. Additional complications are that the ADD moms perceive that time with their child is an ordeal for family members and they therefore limit the child's contact with the extended family. This position is illustrated in the following:

My mother's older. And she can't tolerate their behavior except for short periods. Especially both of them together. I would say in shorter periods. [AD-08]

Most of them know that they are hyperactive and tolerate them when the short times that they're around them. I try not to force them on them. That's the reason, I guess, we stay home more. [AD-09]

A few mothers commented on the genetic link and the complications that causes in the extended family.

It colors, it ends up coloring how you feel about your inlaws, how you feel about your husband, because you know, you say, "Where did this come from?" And you really, you have to deal with those emotions all the time. [AD-05]

[about her in-laws] But trying to do stuff with them would be a disaster. Just like, my theory is, his father just couldn't cope with him. Which is my theory why C. is some of the ways he is. So I see how little his dad can cope, so [inaudible] and it helps me understand some of the things. [AD-18]

But both grandmas are very antimedicine. Both of them. It's not something that we can talk about easily and my husband's mother doesn't even want to hear about the learning problems. Because my husband had learning problems and she knew about it. I mean, she kind of passed it off because she was busy with other things and that kind of stuff. And he just barely made it through school with Ds and Fs and that kind of stuff. . . . So I think there's a lot of guilt and "I made it, I survived," that kind of attitude. [AD-06]

The only ADD mothers who described the type of emotional camaraderie common to CF mothers had other ADD children in the extended families. For example:

(Re: Sister-in-law). She's very good with my children. She's very good with [my son]. The down side is sometimes [my son] and [her son] will butt heads because they have, not the same problem, . . . but the Ritalin problem. You know when they're off of it and the age difference. I laugh with C-. about terrible things. Not everybody can you laugh with when your child has threatened to kill somebody. But because she's been there, you know it always helps when you talk with somebody else who says, "Oh, yeah, I remember when J-. did blah blah blah," it just makes you feel like you're not quite so isolated. [AD-13]

Other mothers find ADD in the extended family a mixed blessing. While they enjoy the relief from apologizing for their children's behavior, the family may also be constraining and judgmental.

She sees faults in my children. Just understanding and the same thing happens to me, and just camaraderie. But she does not have the knowledge. She does not read. She has a severe ADD boy who has just been a heartbreaker with everything that's happened with her. I mean, he's been arrested and shot and a whole bunch of stuff. I'm a support for her, and give her information, but she's just my sister when we talk. But I have to careful what I say. With the other two, I can say anything I want to. With her, I have to be careful what I say, because she will come back and say, "Well, that's not true about your boys." So I put in a censor, in order to protect that relationship, I'm just careful what I say. [AD-05]

Mothers in the ADD group were more likely to rely on individual professionals for support. Physicians and nurses were the most commonly listed "other," closely followed by teachers. These are individuals who are tuned into the unique difficulties associated with parenting ADD children.

How does my tutor say? Attention deficit parents have no furniture, which is true, no friends, because you never get out, because you can't get a babysitter, families are a hassle, because I mean everybody's always on your case because, you know, "If you would take hold of this kids!" as grandma always says, "If you would just give them to me for the weekend!" You know. So furniture, family, friends are final. That's how she puts it. [AD-06]

The importance of professionals may be due to the complex needs of these children. The parents need uncritical sources of guidance and affirmation. The treatment of ADD is inconsistent and many families search for years before finding care they were comfortable with. It seems logical that these mothers would be especially attached to care givers. For example when listing her supports, one mother was asked to rate the physician she had mentioned from one to one hundred in terms of support provided said "seven bazillion . . . she offers knowledge, hope, and compassion" [AD-03].

Health Care Support. Health care as a resource was difficult to measure. The families with CF received comprehensive care through the Pulmonary Clinic at the J.H. Miller Health Center. There were no CF mothers who felt that the medical support and information provided to her was lacking. While the clinic consistently got positive reviews, mothers mentioned the "clinic" or the "team" more than individual care givers.

All of the ADD mother's reported having some sort of private health insurance. Over 80% of mother's complained

specifically about the lack of coverage for ADD related problems in their coverage. Eighteen per cent stated that none of the routine costs associated with ADD were covered. Medications were covered for 82% of families. Many of the mothers had stories of frequent appeals to the insurance company for reimbursement and a lack of intervention options because of poor health insurance coverage and the high cost of private care.

Other Issues. An additional complication in this analysis is that ADD is a familial behavior disorder. It is possible that there are families with ADD persons in several generations that behave in atypical ways. In this case a comparison of family support in CF and ADD is moot because we would be comparing a "typical" family system to an "atypical" one rather than looking at differing influences of the children. Because there are a high number of adopted children in the ADD sample, the ADD sample was divided into a biological and an adopted child group to see if there were differences between the groups.

Differences in the distribution of demands between the adopted and biological ADD is presented in *Figure 8*. The total number of demands listed is by biological ADD mothers is 20% higher than that reported by CF mothers, and 45% higher than that listed by adoptive ADD families. The low number of general demands for the adopted ADD mothers is explained by the high incomes associated with this group.

Distribution of Demands

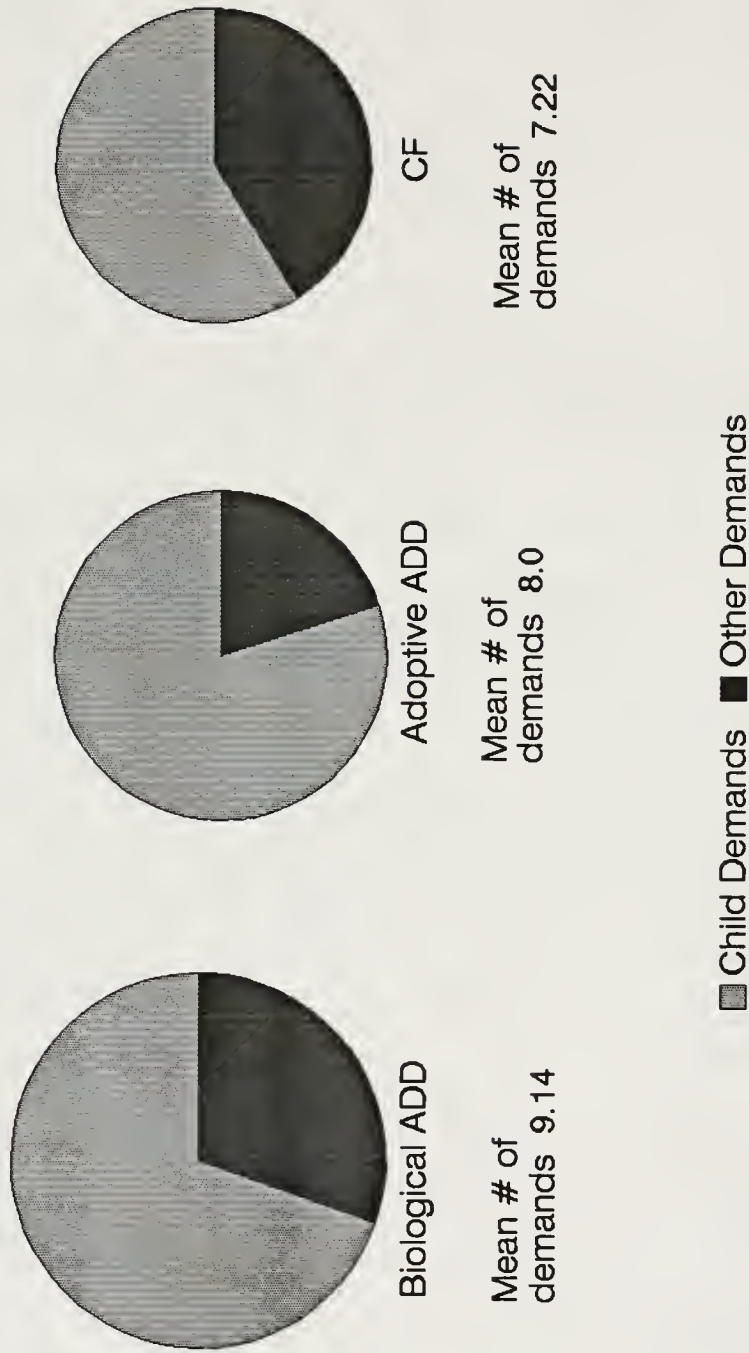


Figure 8 Distribution of Demands: Biological and Adopted ADD compared to CF

Table 7 presents family income for the adopted versus the biological families.

Table 7 Biological and Adoptive ADD Family Incomes Compared

	Income*	
	Mean	Median
Biological (N=14)	\$57,714 STD: 29,173	\$65,000
Adopted (N=7)	\$83,714 STD: 64,226	\$42,000

*one family had one biological child with ADD and one adopted child with ADD. This family was excluded from this analysis.

There is a wide range of incomes in the adopted family group. Three of the families report a total annual income in excess of \$94,000. The remaining incomes range between \$32,000 and \$42,000. Median family income is lower for adoptive families, but the distribution of incomes is quite skewed. Of the seven families, five have incomes well above the median for the biological groups. The remaining two families have very low incomes. This disparate distribution masks the overall financial advantage available to 71% of the adoptive group. In the adoptive group social support networks are also higher. The distribution social support networks in the two ADD groups is presented in *Figure 9*. Although I have no specific measure of health care resources, because access to specialized services is directly related to available finances, it is expected that in ADD health care resources are closely linked to income.

The high mean income of the adoptive families may also account for some of the disparity in perceived demands shown in Table 8. Table 8 presents a comparison of demands and resources for these two groups within the ADD sample. There were more (1.36) non-child related demands in the biological group and little difference in the perception of child-related demands. This supports the idea that financial resources explain much of the difference between the two ADD groups.

There is a dramatic difference in the perception of family resources in the two ADD groups. The adopted families have more (1.36) family supports than the biological families. Mean family support is similar between the adopted ADD group and the CF group. This suggests that the families in this study who have adopted ADD children have more supportive family systems. The biological families with ADD perceive less support and less tolerance within their extended family. Assuming that there are likely to be undiagnosed adults with ADD in the extended family, this may reflect the toll that an ADD family member takes on overall family interaction.

Social Networks

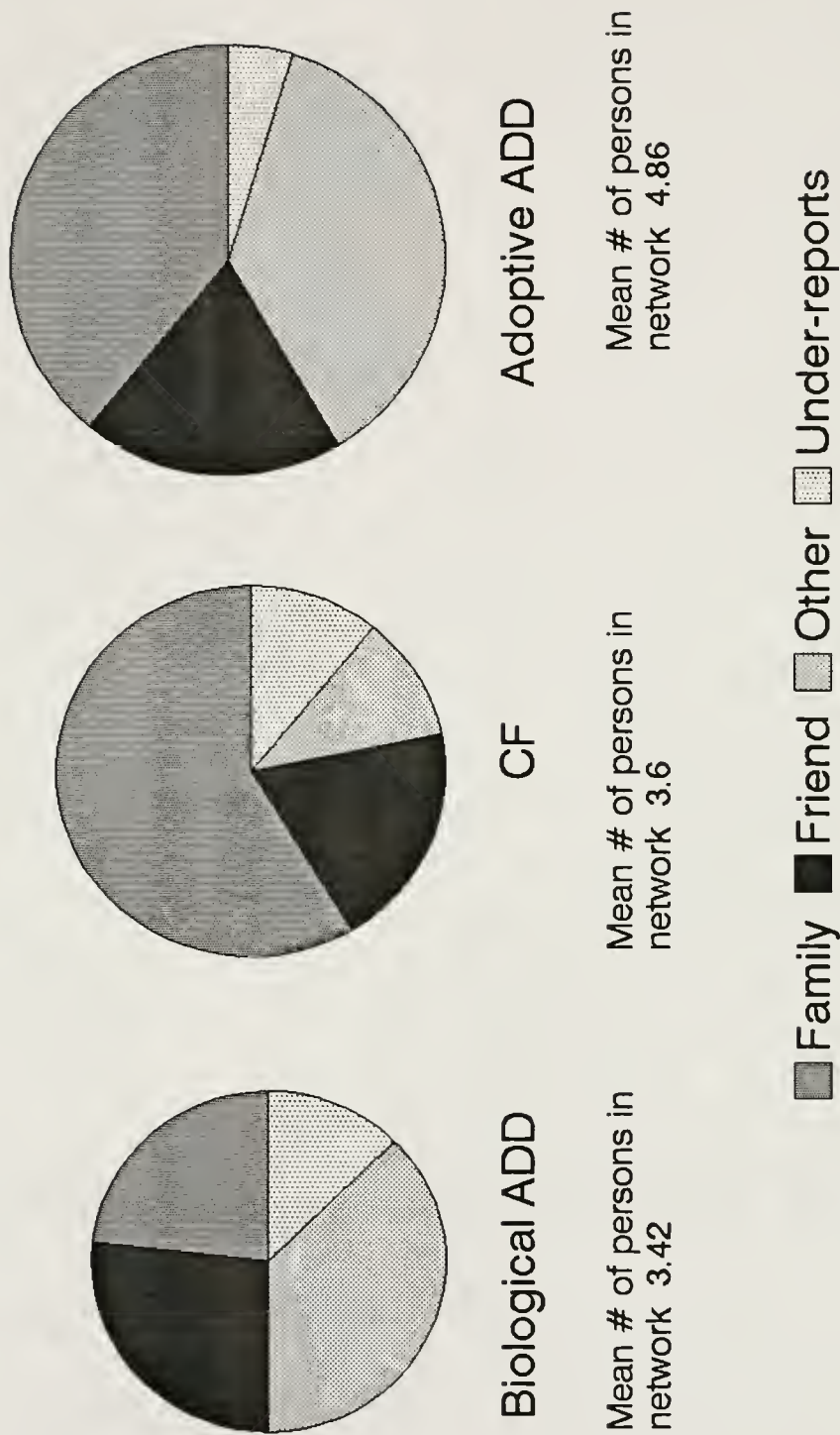


Figure 9 Social Networks: Biological and Adopted ADD compared to CF

Table 8 Biological and Adoptive ADD Demands and Resources Compared

	Demands		Resources	
	Total	Child	Family	Other
Biological (N=16)	Mean: 9.14 STD: 3.68	Mean: 6.07 STD: 2.62	Mean: 0.93 STD: 0.94	Mean: 2.50 STD: 1.61
Adopted (N=7)	Mean: 8.0 STD: 2.52	Mean: 6.29 STD: 2.21	Mean: 2.29 STD: 1.38	Mean: 2.57 STD: 0.79
CF	Mean: 7.22 STD: 4.24	Mean: 4.57 STD: 3.82	Mean: 2.60 STD: 1.72	Mean: 1.33 STD: 1.35

*one family had one biological child with ADD and one adopted child with ADD. This family was excluded from this analysis.

While the overall numbers of persons listed as supports is consistent between the groups, the quantity and nature of available support seems quite different. Mothers of biological children with ADD have far fewer outlets for emotional tensions, report feeling isolated, and have needs that are beyond the ability of the extended family to meet. Mothers of adopted children with ADD perceive a similar number of family supports to the CF group, but offer a less extensive listing of the kind of support offered. There was little difference between any groups on perceived spousal support, with roughly one half all married subjects listing their spouse as a support.

Family Appraisal

Family appraisal is described as ". . . the family's subjective definitions of their demands, their capabilities, and of these two factors relative to each other" (McCubbin

and Thompson, 1991, p.20). Positive family appraisal includes an overall sense of personal control and little ambiguity about role expectations and the action required to cope with the challenge. Specific threats to a positive appraisal are "role strain because one can't meet the high expectations set for oneself . . . [and] lack of a clear definition about how to cope" (McCubbin and Thompson, 1991, p.20).

ADD mothers face more threats to family appraisal than CF mothers because of the controversy surrounding the diagnoses and treatment of ADD. Mothers dealing with CF are given specific behaviors and conditions that need to be met to care for their child: there is no ambiguity in the definition of how to cope. ADD mothers are faced with many "prescriptions." Strategies are offered by health professionals, teachers, family, and strangers in the grocery store. The ambiguity about positive actions, and the implication of poor parenting places ADD mothers at a disadvantage in developing a positive family appraisal. Appraisal was determined in this study by considering comments coded as: vulnerability, intervention, vigilance, normalization, positive comment, negative comment, child-focused routine, "why me?," and "I feel guilty." The category of faith was originally treated separately from overall tone as an additional measure of appraisal but it

did not appear to add anything unique to the analysis³. High appraisal is expected to be associated with a high social network, high income, and low demands.

Each transcript was reviewed and assigned a label of "positive," "negative," or "neutral" based on the overall tone of the comments. This analysis is organized in Table 9. This analysis is consistent with the trend noted earlier.

Table 9 Appraisal Summary

	Negative	Neutral	Positive
CF	4	8	10
ADD-total	12	6	4
ADD- adoptive (6)	2	2	2
ADD- biological	9	4	2

Figure 10 illustrates the appraisal of respondents in the CF and the complete ADD group. As expected the ADD group is predominantly negative and the CF group is predominantly positive. Because the the differences noted earlier in the adoptive and biological ADD groups, appraisal was also analyzed for between group differences. Figure 11 presents this analysis. After separating the two ADD groups, CF mothers continue to have the highest family

³ There were no specific questions about faith in the interview. Faith was coded when directly mentioned and with the mention of religious gatherings or clergy. It is likely that faith is under-reported in the CF group because so many ADD mothers mentioned it in the context of how difficult managing their children was while attending the service.

appraisal. The family appraisal in the adoptive ADD is slightly lower. The biological ADD group is very negative in its appraisal. Markedly more so than either of the other groups.

Figures 12 and 13 present the influence of demands, income and social network on appraisal in the ADD and CF groups. On *Figure 12*, the ADD graph, the influences on appraisal are consistent with expectations. In this CF sample, relationships were not consistent with expectations. *Figure 13* demonstrates that family appraisal is little affected by family income or social network. The availability of health care was the most important resource difference between the two groups. Based on this finding, access to specialized health care appears to be the greatest influence on positive family appraisal of those studied. The responses on appraisal and each of these variables was graphed for each group in *Appendix C* through *Appendix F*. In addition, number of children in the family was graphed with appraisal. This was considered because the ADD families had both more children and higher incomes. It was expected that additional children might reduce the positive influence of high income.

Families with ADD fare more poorly than families with CF on all aspects of the RMFSA, and the biological families are more impacted than those who have adopted ADD children. Based on the context of these interviews, the higher

Mother's Outlook/Appraisal of Family

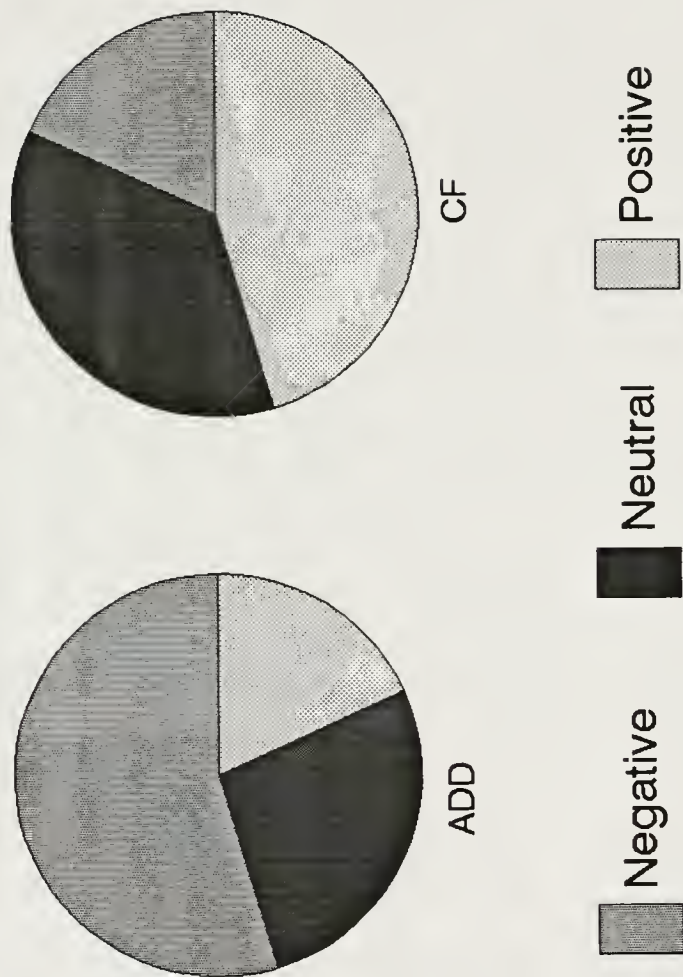


Figure 10 Appraisal: ADD and CF compared

Mother's Outlook/Appraisal of Family



Figure 11 Appraisal: Biological and Adopted ADD compared to CF

demands, coupled with lower social-emotional support strongly influence family appraisal. No questions in the interview led to an appraisal of themselves as mothers, but the fear of being considered a "bad mother" was frequently cited in the ADD interviews. This seems to be the fundamental influence on family appraisal in both samples.

Mothers of children with CF had a concrete set of behaviors expected of them to maintain their child's health. Following these routines, they had happy well behaved children with no visible problems. These mothers seemed confident in themselves as "good mothers." Most CF mothers focused on how "normal" their child and their family was.

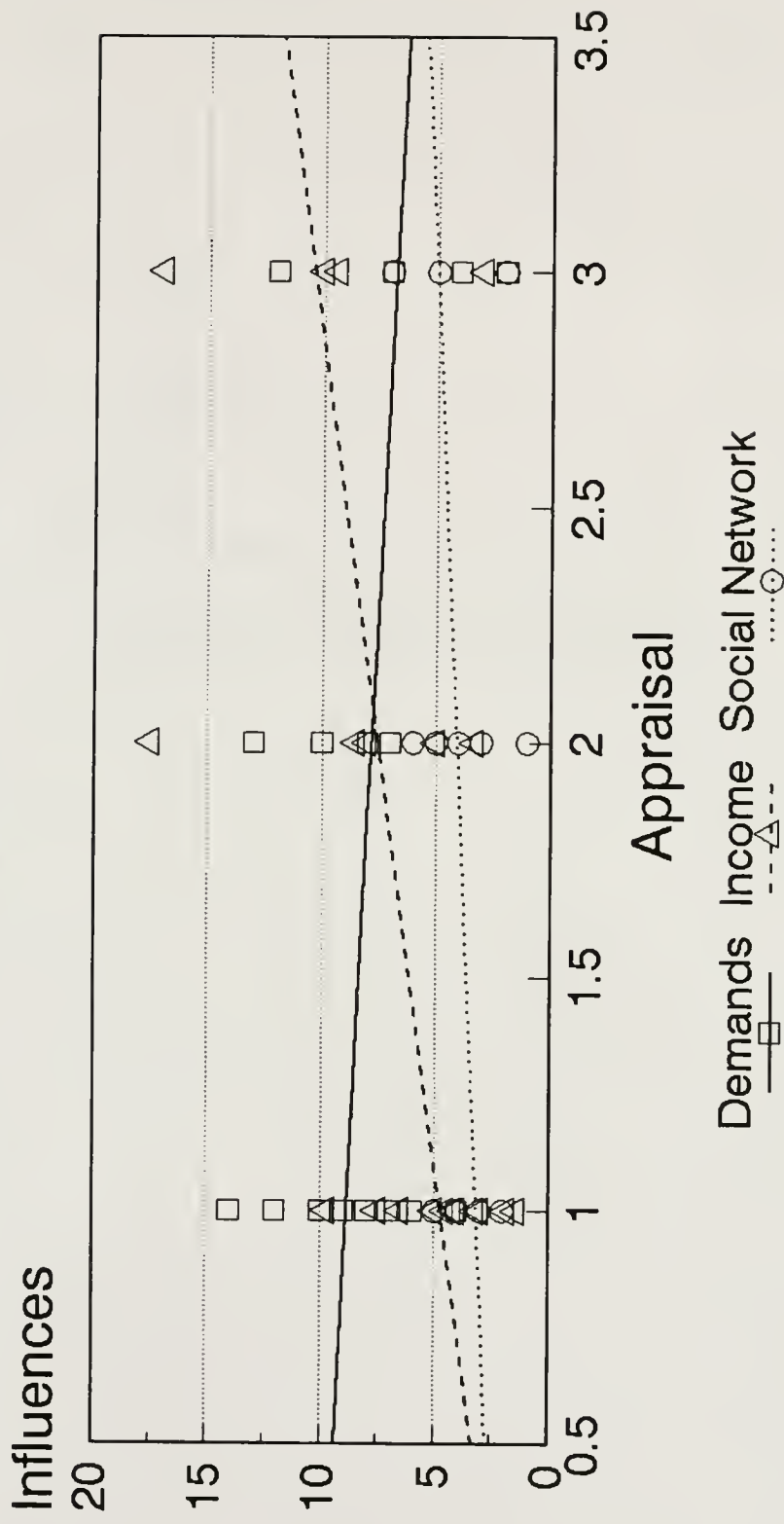
The mothers of children with ADD had no clear prescriptive response to the problem. These mothers reported an ongoing search to learn all they could in order to make good decisions.

Your life accommodates them. The running around, and the special appointments, and the stacks of papers that go with it and the information things that you seek out and read. But it all depends on the person, too. I'm a person that has to research what's going on. I may get too much or I may get too little, but at least I'm going to know something about what's happening. And I've read many books. [AD-07]

Many reported social sanction and high demands placed on them by the school or medical communities.

The other thing is, the attitude of most of the teachers that I run across, is that, hey, they can be home at 3:30 or 4:00 and work with their kids for three hours a day if they need to. That's wonderful.

Influences on ADD Appraisal

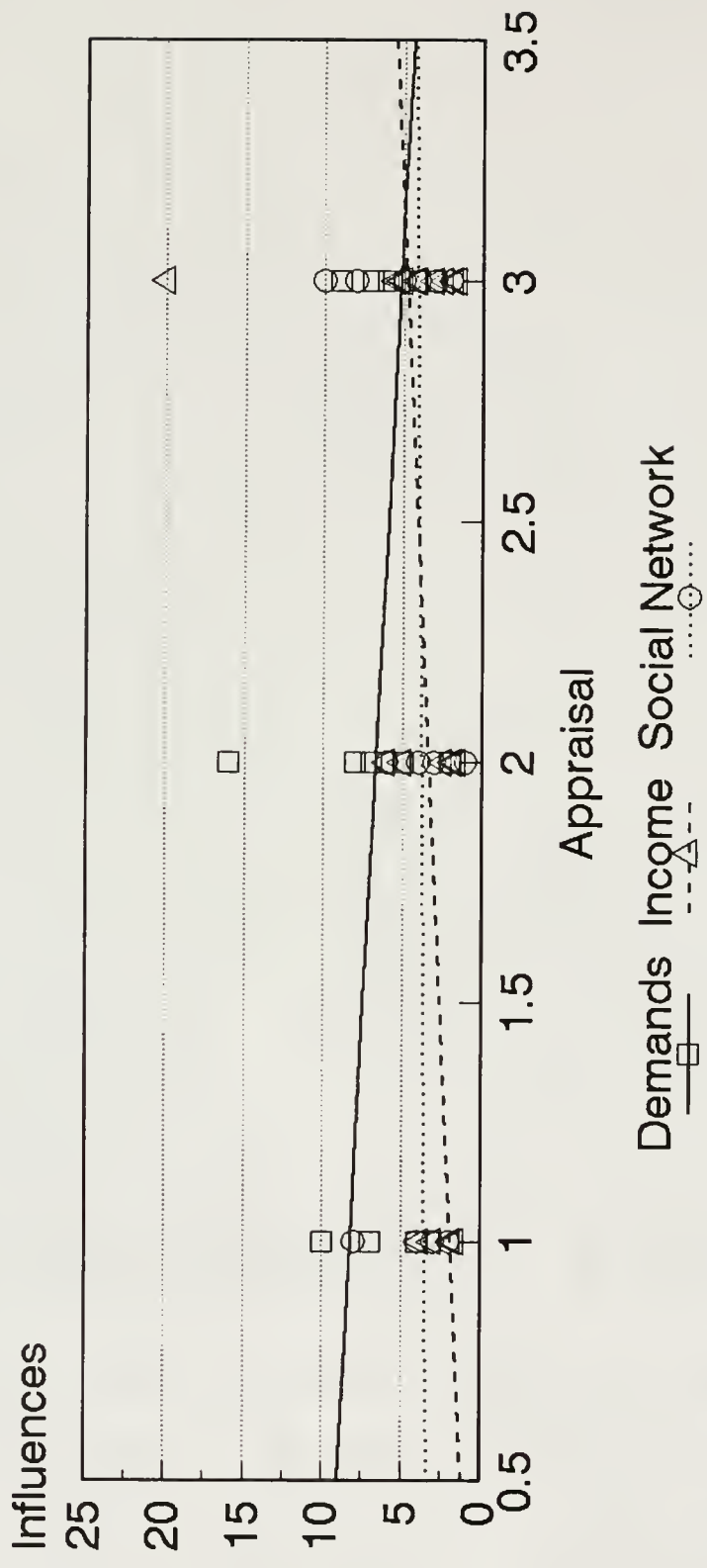


Low Appraisal scored 1
 High Appraisal scored 3
 Income is in ten thousands

Figure 12 Influences on ADD Appraisal

Influences on CF Appraisal

Influenced by Income and Demands



Low Appraisal scored 1
 High Appraisal scored 3
 Income is in ten thousands

Figure 13 Influences on CF Appraisal

Unfortunately, it's not reality for the rest of us. And so their attitude is that you're just a lousy mom if you can't spend two or three hours a night with your child working on this specific thing. That's not real and it's a real barrier block. They're not up to date on what the life is like for the parents out there. I won't get on my soapbox. I pick up my kids at 5:30. By the time we got home and get out of the car it's closer to 6:00. I have to make dinner. By the time that I pick them up, D-. and L-. are both completely off their Ritalin. It's a four hour effect, they take it at noon, they're covered at school. By the time I pick them up, they're off. Okay? Trying to get an ADD student who's working below level to sit down and do his homework every night, and for some reason right now, third grade they've decided should be the homework capital of the elementary school. So I think for a non-ADD child, it still would be an hour's work of homework a night. For an ADD child, we're talking two hours, easy. And that's if you can sit with them and say, "Stay focused. Okay, concentrate on what you're doing. Now what's next. Now what do you have to do?" The reality is, I've got two other kids that are running around screaming and jumping that need some attention, need food, need baths, need me to look at their stuff. I don't, it's not feasible. And so it becomes this huge war. "L-., why aren't you sitting there and doing that? L-., turn around and do your work!" "Okay, D-., what are you doing?" I mean, you just, it's like this brick wall. And the school is totally unresponsive and they don't understand. It's just not appropriate. They have an after school program. I've gone in and spoken to the after school program on several occasions. I want my kids to sit and do their homework until they are done. And if it means they miss the rotations that they do in after school, then they miss the rotations that they do in after school. I have a much better chance of them getting their homework done at 3:00 when they get to the after school program than I do at 6:00 when they're hungry, tired, and cranky. I can't do it.[AD-15]

Mothers of children with ADD reported a persistent social innuendo that they were at fault as mothers. None of the mothers interviewed felt that they were entirely to blame for their children's difficulties in school or social settings. As one mother in the study reported,

We're always blamed for it. People think you should be able to control your child. I used to feel the same way, with my other children, when I'd see a child misbehaving. I'd think, "What's wrong with this parent? Why can't she control the situation?" I didn't know. I was just like them. [AD-02]

It is in this area where resources were most likely to come into play. For instance nine of the ADD families had their children in private schools and the mean income of these nine families was \$94,000. The adoptive mothers had slightly less stress because of the belief that their child was better off with them than they might be in the foster care system.

I think you think that until you finally figure out what's wrong with him, that you've somehow failed this child and you wonder why and how what you'd do differently. But I think once you kind of said that he's attention deficit and that this is not a control thing, and can understand it more, then I think it relieves any guilt that you ever had. Especially, I think, if it's an adopted child, it's, you so wanted that child to begin with that he just came into this big basket of love. [AD-04].

Mothers of children with ADD consistently reported that receiving a diagnosis for their child was a relief. Only in the instance of second or third ADD child diagnosed within a family was there an expression of distress. The following is a common type of response.

How did you feel when your child's problems were finally diagnosed as ADD? Split. I think one part of me was relieved that there was a label that I could learn about and understand. I think the other part of me felt, "Why do my kids have to have this problem? What did I do that my kids have this problem?" Tell me the story leading up to your child's diagnoses. I became close friends with somebody who had a very complex child. One of her labels is ADDH. Up to that

point, I hadn't really labelled my kids. I just thought my kids are just, oh my god, I'm a terrible mom. So as I became more in tune with this family and more friends with this family, and I started hearing ADD and discussing it and started researching, and it was like, "That's my child! This makes sense! Wait a minute, I recognize these patterns!" So when I took them in for a check up, I started talking to their pediatrician and discussing everything. And she gave us forms to fill out and we just started the cycle from there, discussing what it meant and all of that.

The diagnosis was considered a relief because it affirmed that the child was not "normal" and was therefore difficult to parent. It alleviated much of the self-condemnation of the individuals ability to mother their child. In addition it offered new directions to seek help. Following diagnosis mothers with good financial resources responded with positive action.

One way is to go into action counseling, tutoring, physician, teachers, school situations and go to try to do the very best I can do and I know that. And I have to step back and say, I can't do everything. And that makes me trust the universal things you trust in. My strategy is to do the best I can do, get all the support I can, and then trust that that's going to make the difference.[AD-12]

Mothers with fewer resources had the same concerns for their children, but were less able to pursue community support. These mothers more dissatisfied with the community resources available to their child.

Where he is now, he changed schools and I'm a lot happier with that. But there's still a lot of things that I wish could be done. So I'm not completely happy. But I don't know if I'd be. You know, I have an idea of what an ideal setting would be, and I don't know if that would exist anywhere . . . Oh, one thing they pointed out to me, talking about the dissatisfaction with school, is they say an assumption I make is that they really teach, you know, when the kids go to

school, you think they're going to teach them how to write, and they don't. And everything I read in the magazines and everything said, they were saying that educators were telling parents, "Don't teach them to write, because they're going to teach them how to do it right in school, and what you teach them will conflict." So it's like he has a problem to begin with, and . . . what we're doing is remedial. The school system doesn't understand, I don't think, what ADD affects. And they let him go and let him go until it is so bad, then they say, "They need help." The parents are there assuming, "You're doing your job, you're doing your job, you're doing your job." [AD-16]

The RMFSA offers a useful structure to assess the relative strengths and weakness that the individual mother perceives in her family. It offers little in terms of explaining why these differences occur.

Normalization Theory

The study of normalization was not initially a primary focus of this research. As themes developed it emerged as significant and was pursued through elaborations on the original interview questions. The frequency with which the words normal, ordinary, and routine occurred in the CF interviews was striking. It was especially striking when compared to how seldom those words were used in the ADD interviews.

The fundamental premise of normalization is that individuals make sense of chronic illness and life disruptions by constructing a "life as normal" story that includes a past, a present, and a future. CF, in many ways,

is conducive to this sort of story building. When asked "Tell me the story leading up to your child's diagnoses" mother's of children with CF usually had a short coherent tale like the following examples.

Tell me the story leading up to your child's diagnosis. Well, she was fine until I brought her home from the hospital. I was nursing her. She was doing great. She was growing. She was gaining weight. She was doing good and then I got like strep throat, ear infections, I just got real sick, running real high fevers and for a long time, like a week and a half, two weeks, my milk kind of dried up from lack of being able to eat and keep stuff down and drink and stuff. But anyway, we had to start putting her on formulas. And that's when our problems started. She started throwing up and having diarrhea and that was at 3 months. And then finally at 6 months, everything just clicked. They had diagnosed her as failure to thrive. And then we started noticing the true blue symptoms of cystic fibrosis. And we kind of all just fell in together. And we had her sweated and she turned out positive. And it was a rough 3 months. *After you got used to the label, how do you feel about the problem?* It's just part of life. It's just like I said, she could have a lot worse. She could have heart disease or liver or kidney disease or she could you know, have far, far worse than CF. We're just thankful that that's all that she does have and she doesn't have any other complications along with it.[CF-07]

It wasn't until two weeks before delivery that we started to suspect it. I was very devastated. I was crying, "What if it is?" and wondering how it was going to affect my life. But you know, we just took it one step at a time and her birth and the surgery that she got and that kind of thing and then we had the CF test and it came out positive and you know, you just kind of go on one day at a time and it wasn't as bad, I have to say, as I first thought it would be. And I think N-. 's done real well herself. There are a lot of things other people might experience with a child with a serious illness, we haven't experienced those things. The problem has been very mild. [CF-8]

Mothers of children with ADD had a longer, less threatening period of dealing with their child's problem

without health care support. As noted earlier, several of the individual children in the study had been diagnosed less than a year before the interview. The defining criteria for "normalization" of daily activities include an acknowledgement of the impairment and minimizing the social significance of the problem.

Normalization research has not focused on chronic behavioral deviations that provide a social threat to the family. The experience of mothers of children with ADD provides a test of this theoretical model. The ADD mothers' diagnosis stories are very different than the CF ones. A major theme in the ADD stories is the amount of vigilance and the stress that vigilance caused as mothers tried to keep their child safe and out of trouble.

He never stopped, ever. And he's very amusing. Even to me now, I mean, he's extremely witty, and people always say how smart he is, and he just whatever, but it was like he was always on. He was always on. And I always thought, "Wouldn't it be wonderful if he had a little switch to turn him off and stick him in the drawer and put him away for the rest of the night." But he was just real different from the other kids. The other kids would be like bumps on a log and here was this kid that just wouldn't stop. And then sometimes he really got so wound up that it was pathetic, and you know, when he got older and could verbalize and stuff, and I know that he got confused and he didn't understand half the time because he was just like this little top out of control. You know, and I knew he didn't understand what was going on. That was kind of pathetic to watch, you know, when he got that wound up. So no. In kindergarten, at the point that the teacher told me, I knew that she was right and that there was something. He just couldn't sit in his spot and he wasn't being malicious or anything, but he just couldn't do it. So I suspected.[AD-08]

Well, S-. was a second child and you know, a second child is often slower to do things. [inaudible]. But S-. was a really beautiful compliant baby. She slept well. She did, she could calm herself. But even at 18 months she was active and getting into things. [inaudible]. We could not sleep at night for fear that she was going to get out of bed and tumble down the stairs. Or, go outside the house. She'd wake up and she'd be ready to take on the world. In order to get any sleep, we used to lock her in. We must've been totally stressed. But it was mostly fear of her hurting herself. I did spank her a few times. One time for sitting in the pasture under the horse. She was actually sitting underneath the horse. I thought my heart would stop. [inaudible]. I thought we had trained her and she figured out how to open that gate and she was sitting there under the horse playing in the dirt. And I took her up to her room and I spanked her. I thought, how am I going to get through to her if I don't do this. [AD-12]

The process of normalization has several component parts. For people actively to construct a story of their life as "normal" there needs to be acknowledgement that there was a chronic condition. The problems associated with the chronic condition are accepted but minimized. The management of normalization involves predictable type of behavior among family members. These behaviors include covering up, doing "normal" things, desensitization, and making trade-offs (Knafl & Deatrick, 1986). Desensitization has to do with making people familiar with visible differences. This strategy was not employed by either subject group. The strategy of making trade-offs was used only in the sense of providing specially tailored environments for the child. For example, about one third of the families in the ADD sample had placed their child in private school settings. In CF the failure to use group

child care facilities also had the effect of controlling their child's environment. The trade off is acknowledging the problems of a typical environment and providing environmental accommodations that allow their child to function "normally." Other strategies common to normalization, covering up and doing normal things, are discussed below in terms of CF and ADD.

Covering Up

Consistent with Robinson's (1993) finding, families focused on the aspects of their child's life that were patently "normal." When the subject of the CF child was brought up many respondents described the child's talents, academic performance and extracurricular activities in great detail. Many families emphasized their child's physical activity as a means of strengthening the child's respiratory capacity.

We were very fortunate that the medical institution had a very good physician. He operated on her bowel obstruction, and basically N-. I think has led a very active life. I mean, she takes a lot of dancing, she's a cheerleader. I mean, to look at her, she looks very healthy. And she does very well. It's not really a prevention, but we're preventing problems from happening, trying to give her the best care we can. She's done pretty good.[CF-08]

She varies a lot. Like in some situations, she's more shy and I think that's when she's not sure of herself. in other situations, she's more of a standout and being forward and more boisterous. I tend to think she's less mature than kids her age. So there's that. That perhaps because of the kind of [inaudible], so maybe

that's rubbed off there. She's excellent as far as she loves to be the stage. And she's been in musicals and things like. So she's capable in certain areas more so than others. Academically, she fights for everything. She doesn't have a lot of memory skill, but she has more memory skills, it's a hearing thing. She does well in music. She can pick up a violin and play it. And she has natural ability that way. But if it's the written word, she has more difficulty. So it depends a lot on where she's at, who she's with, and what it is. [CF-17]

In the context of covering up (i.e., making disability related problems less visible to outsiders), both groups scheduled their medications and specialized care routines in the early morning or late night. Special care, including the taking of medications at school is minimized. In fact, most mothers had normalized the CF to the extent that they fail to report hospitalizations as stresses.

ADD and CF are largely physically invisible. So covering up was unnecessary in the sense described by Robinson (1994). For ADD, covering up might be extended to the use of stimulant therapy outside of the academic setting. In fact most ADD mothers proclaimed the initiation of stimulant therapy as the best thing that ever happened to both their child and their family. In the case of ADD, medication offers a "cover up" or hiding of aberrant behavior. Mothers report using Ritalin to help with family gatherings, religious meetings, parties, all sorts of challenging social situations. Ritalin is highly touted in most transcripts.

What stands out as being the most helpful thing you've tried? Other than being on medication? I think the

medication is. He seems to me what I would say a "normal child." He reacts normally to circumstances when he's on his medication . . . Well, people that know him and have seen him on and off, it's a distinct difference. You can tell, if you know my child, if he's on his medicine. So most of time, I think because he was such a hard child until we figured out what was wrong with him, he tried to burn down his bedroom, he got a flame lighter in there and had the bed, the wall. I mean, I have some great stories about this child. So they all knew that he was a challenge. And so then if they know that, then they know he's on the Ritalin now, and things are better. [AD-04]

I don't know, maybe just because I'm sensitive about it or something, but sometimes I think he doesn't have a lot of friends, even though he's been in this school forever . . . he doesn't get invited a lot of places. And he doesn't have that. But he doesn't seem to mind, either, so I quit worrying, or tried to quit worrying about it. But I think some of it is the parents can't deal . . . I kind of feel like parents don't want to deal, you know, with this, and so I think that's pretty much why he isn't invited. Although, you know, I would give him a dose, you can invite him. [AD-08]

Maintaining a Routine

Although generally describing the diagnosis of CF as "devastating," this usually marked the beginning of the "life as normal" story. With the diagnosis mothers were given specific prescriptive actions, medications, and support for their child's condition. As noted earlier, most of the CF mothers had been performing these prescriptive behavior for several years. Most CF mothers described brief mourning followed by the sense that they had to "do everything possible" to keep their child healthy and provide an idyllic childhood.

Routines were important to the perception of control in both groups. Mothers in both groups who described their life as routine were consistently positive and those who described their life as chaotic were negative in their family appraisal. A good example of routine in dealing with CF follows.

We live a routine life. Day after day, same time every day practically doing the same thing. Our routine very rarely changes without something happening. In the beginning, of course you start . . . you get yourself . . . when we found out about with M-. it was a matter of getting used to it. You do have to get used to it. But he is going to be 12 . . . its been a lot of years. Its really a pattern. That if we are on vacation or something, and its not routine, we can get disturbed . . . because we're not used to that. You can get very dependent on that . . . and that is the way we live. Anything else throws you off. It would be like someone else tomorrow morning time and live our routine . . . it would be very hard for you to get up, to give your child medication, therapy, and get it all done and get yourself something because you are not used to doing it that way. Because of need for medications, meals are at certain times . . . snacks pretty much certain times too . . . When I talk to you about it, I realize that everything is very routine . . . highly. I just never thought of it that way.[CF-12]

One of the common strategies of "doing normal things" is a focus on discipline and treating the child "like any other child." This was commonly mentioned in the CF interviews. "Special" treatment at school or from family friends was generally frowned upon. The issues were different in ADD. Discipline was one of the disability related problems. Many mothers reported that they had "lowered their standards" or that they "chose their battles." Lowering performance standards was a common

method of reducing stress in the family, even though several mothers reported that it caused conflict with siblings. In the case of ADD discipline was sometimes sacrificed for a routine and for a level of family conflict that allowed other family members to function "normally."

I might let him get by with a little more. Probably not discipline wise. Mary said the other day, "Mom, he is in first grade. He doesn't make up his own bed and I had to start making up my bed." It's a real thing with R-. of trying to even get him up in the morning. Because he is a slow starter . . . So I guess in that respect where I won't let the girls get by with things. "It's time to get up. Get up, get dressed, get the beds made." Whereas with Richard, I still help him get dressed, because I guess I realize it takes him a little harder to get the engines all going. And they, I guess maybe I'm more lenient in those ways. But he will eventually get up and make up his bed, I hope to tell you. I just have to use a little bribery.[AD-11]

I think I let some things slide. I try to limit the confrontations to important stuff. R-. has always needed more [discipline] than J-., but it's been OK till recently. The combination of the moodiness and lashing out and his size. I mean he's turning into a man. He's much bigger than I am, and so it's a little harder to be intimidating. And is it worth it? Is it worth all the bad feeling we end up living with? [AD-21]

Normalization theory focuses on the use of specific strategies like covering-up and maintaining a routine to create a family story of life as usual. In ecocultural theory, Gallimore et al. (1989) emphasize the beliefs families construct about everyday routines. These beliefs support the specialized "normal" life of that family. This was prevalent in CF where everything from nebulized breathing treatments to IV therapy at night were hardly

noteworthy. These treatments were mentioned only after specific questioning about medical and personal routines.

Also, there was a pulling in of the social network in CF. Mothers reported having close families and seldom engaging in activities that did not involve the children. A close circle of family and friends were well informed about the disease and daily care issues. Beyond that well defined social niche, mothers offered little information about their child's disability. Several mothers said that they told the necessary school personnel about the CF but "it was no one else's business." After that it was the child's prerogative to tell about or keep secret their condition.

Have you changed or limited your social contacts? I don't know that I've changed or limited it, and talking to other people I've found the same. It changes. A lot of people are uncomfortable around other people's children, but especially if it's considered a terminal illness and some people just sort of disappear from your life. On the other hand, we've gotten to know a lot of people that are connected, their family members or adults with CF. Another thing is, I remember I was talking to someone who had a child with, he was diabetic, and he said that you know, we were talking about your priorities change. And so, I didn't find this as much as he did, but he felt like he didn't have anything in common with some people, because what was so important to them, you know, the most important thing in their life, was very low on his list of priorities. [CF-05]

ADD mothers aspire to, but have more difficulty attaining a semblance of normalization. The impulsive and erratic behavior of many ADD children make it difficult to sustain daily routines. Families describe the "off medicine" times as trying and chaotic. For example:

In the morning, we get up. I get up at 6:00, but my husband doesn't get up. We don't wake the kids up until quarter to 7. We leave the house at 7. And I say, "We've got to get these kids up earlier." And he says, "What for? We'd have to deal with M-. all that much longer." We just get him up, we just deal with him for 15 minutes, and that's it. Get dressed, put your shirt on, put your shirt on. You know, you tell him, put your socks on. And he's not on--obviously, he takes his medication, but that's not going to kick in for quite a while, 45 minutes. I've been tempted to get him up and give him medicine and then put him back in bed. It's horrendous. Those 15 minutes. You know, you're screaming like an idiot, "You don't have your shoes on. I told you to get your shoes on." Because you're just trying to get out the door at 7:00. And it doesn't matter. You can wake him up at 6:15 and you still go through this. You just have 45 minutes of this. So I don't know. Yeah, the mornings are definitely the most horrendous.[AD-08]

Although these parents develop strategies to deal with the challenges they face, the accommodations are extreme and beyond their ability to consider "normal." Families with ADD seem to experience a degree of social isolation that is mildly distressing in the attempt to structure their child's life in a manner that does not challenges social mores.

Normalization is a concept that refers to a means of achieving a degree of social conformity or normalcy. This construct is widely used as a measure of successful adaptation to chronic disability. Because ADD is a socially manifested disorder, families are unable to consistently attain normalization, and feel unrelenting social pressure as a result.

Model of Human Occupation

Occupational behavior, in the context of this theory, has to do with those behaviors an individual needs to master to achieve life satisfaction. This model emphasizes the importance of personal perceptions, roles, role expectations, and role related behavior. As noted earlier, the "mother" role has no clear parameters. Rather than a prescriptive set of expected behaviors, mothering is assessed by child appearance and outcome. Because the outcome measure is to some extent outside the mothers' control, mothers of children with chronic conditions must respond to the challenge in atypical ways. For example, a recurring theme in both groups was vigilance. Mothers in both groups described the sense that their child was "a time bomb ready to go off." The major impact of these two disabilities on the mother seems to be in the environmental and volitional subsystems.

Role expectations play an important role in the mothers' reactions to chronic disability. Mothers either by themselves, or in response to environmental press take on the role of caretaker, protector, and cheerleader with great gusto. Mothers in both groups described their spouses as "good fathers" but ineffectual in the day-to-day management of child-care routines. In both cases mothers described

fathers as more distant, and in the case of ADD less accepting of the diagnosis.

ADD mothers repeatedly mentioned "I feel like a bad mother" "I'm so embarrassed" "I'm sure they think I'm a bad mother" and "I'm not a bad mother, but. . . " For most of these mothers the point of diagnosis was a relief. It was an affirmation that they were indeed dealing with something different. Some had long struggles with themselves even after the diagnoses.

Have your interests have changed since you have been dealing with your child's special needs? It would be nice to shave my legs and stuff once in a while. Now it's like I'm more "me me me" this year, when I've decided that this is it. Like I say, I truly felt, not a joke, that my life was being sucked away. I spent all the time with this kid after school. I was working these crazy hours, 4:00 AM to 2:30 in the afternoon, so I would be there to pick up these kids . . . To pick them up so they don't have to go to after school care so they can go straight home and do all this junk for school. And then I neglected totally my older son, which then now he's going through all of these puberty and everything else, and it's just like, you know, I'm overwhelmed. And, you know, you feel guilty. And I try explaining to him, "You know, your brother has a problem, blah, blah, blah." . . . And pretty much I've done this on my own. My husband couldn't help. [AD-08]

Mothers of children with CF also become totally involved with their children. Their issues and attitudes were different though. The imminence of death in CF has a pervasive effect on personal decisions. Many of these mothers subjugate their interests in order to be an idealized "super-mom" who is always there and always loving. Accommodations range from moving to a better climate to putting their clothes in the dryer a few minutes every

morning so that they don't have to dress in cold clothes. A good summary of this perspective is in the following excerpt.

I would say it's like a monster in a little boy that's waiting to come out any time it can. And it just, you don't know when or where it's going to come out and how severe it's going to be when it does. And I know about the disease and I've done a lot of reading about it and everything else. And I understand how it works and everything. But you never know what the severity's going to be or how severe it's going to get and how quick and you know, you're just always wondering what is going be, what he's going to have to go through the next week, or the next month. It's just, I know about the disease and how he got it and what the outlook on his life is, which isn't very promising, and that's one reason I've just chosen not to work and just to make it more or less, I'll suffer without things, just so I know that you know, I'm doing the best I can to keep his life and his health at a point. They say that he doesn't have a real severe case of it yet, or whatever. But I just feel like it's all in the care they get and all in the one-on-one care that they get. It can be as severe as you let it get, if you don't stay on top of it. It'll kill him. And so you've always got to keep it, knowing in your mind that you're getting that crap up out of his body. Because that is the main thing that's going to happen. He's just going to drown in that. [CF-02]

Environmental Analysis

Success in the mother role is commonly measured by child outcome. In the case of both chronic conditions mothers have no chance of succeeding in this outcome measure. This creates a great deal of role strain and emotional turmoil. The CF mothers fare a little better because the social environment offers them the sympathy and consolation of a "sick role." ADD mothers look toward the

high probability of socially marginal or unacceptable child outcome. The lack of social credibility afforded ADD leaves them open to the judgement of inadequacy. Also, because ADD persists into adulthood, these mothers do not see their suffering as time limited. While the CF mothers count down the days they have left to enjoy their child, ADD mother count the years ahead of worry, frustration, and social isolation.

So how does this relate to the Model of Human Occupation? The environment is clearly an influence on the individual's appraisal of themselves in the mother role. Environmental expectations for certain behaviors is called environmental press (Kielhofner, 1985). The atypical demands placed on mothers in both groups challenge their perceptions of the behavior and skills they need to successfully mother their child. While "mothering" is a social role, it lacks prescriptive behavior. The absence of clearly defined tasks leaves mothers to rely on social and intrinsic affirmation of their performance. This leads to much self-criticism and makes analysis of the role impossible the protocol proposed for use with MOHO (Cubie, 1985).

The environmental press includes social, cultural, and familial expectations for mothering. The disability of the child adds demands to the environmental press. The lack of social credence for ADD adds to the difficulty for mothers

of ADD children. Any strain they feel or express is likely to be discounted because their child is "a brat," implying poor parenting. Like ADD, CF mothers were selective about informing people of their child's condition. Unlike ADD, when people were informed about the CF the mothers were met with sympathy, support, and a certain lenience in social performance. In most cases both parents work cohesively in CF families. In ADD there was frequently a division between the parents in beliefs and behavior expectations for the ADD child.

Volitional Analysis

Although there was more "environmental press" than that experienced by mothers of more typical children, the CF mothers were generally positive about their child, their family, and their role performance. There was always a daily medical care protocol for their child. While it varied in complexity, the treatment of CF was clear and unambiguous. Although additional physical demands existed most mothers considered these nominal. The big pressure reported by CF mothers was emotional. The preeminence of early death with CF left the mothers feeling helpless and fearful. They worked hard on medical protocols and family time to try and maximize their child's life and create an

idyllic childhood. In doing so they described a quiet undercurrent of emotional tension.

Have these concerns changed since your child's disability was identified? Oh yeh, my concerns, my whole outlook on things. You know, just how I relate to other people even. It just makes me realize what's important. It's not what you have in your life, its who you have and how much you care for each other and . . . how short it is. [CF-02]

Do you think there are additional emotional demands on you? Yeah, now that there is. It mostly is that. It's just, I have a real soft heart, and it seems like I feel everything he feels and, you know, I try not to, every time he coughs I want to burst out crying, but I can't do that. But I always think about doing it. So it's real emotional. It's emotional for everybody in the family. [CF-10]

Do you feel that there are additional emotional demands? Well, I think that when you're dealing with anybody who has a chronic illness, that is going to get progressively worse, it's a nag, it's a pain. It's always there. And I think it raises your stress level, not to the point that you can't function, but I think you have different concerns. Does that kind of answer the question? [CF-08]

The emotional vigilance described by mothers of children with CF impacts their sense of personal control. The fact that they cannot stop the disease progress or protect their child from the unpleasantness associated with the disease progression leads to a sense of helplessness. Perhaps the focus on idyllic childhoods is an attempt to alleviate this press.

The role of mother for either disability group requires a level of vigilance that influences all other occupational behavior. The reason for the vigilance varies for the two groups, but the effect on the mother is similar.

I never relax. J-. is hard to describe. He is a very sweet affectionate child, but he can also be very destructive. He is so impulsive. I mean he just does whatever comes to mind. Really- anything. It is a constant pressure on me. I always keep him in sight. Playing in the yard, I work right here by the window so I can always see him. He needs to see me too. Like, He'll pick up this stick and start to throw it, he'll see me in the window and will drop the stick. Just my presence averts a lot of behavior. No one else really appreciates how vigilant you have to be. I just never relax. I really can't use sitters . . . All my time is in some way tied up with the kids. J-. requires so much vigilance that I can never let down my guard. [AD-13]

I think there is probably not a day that goes back that I don't think about what the weather's doing, who J-.'s coming in contact with, you know, do they have colds. Environmental things that could affect his health . . . [Also] he's not as responsible as I think he should be, and that causes stress. I mean, like I mentioned before. Is he taking his medicine, when will he do his nebulizer, will he remember to do it before he goes to bed, or will he just go to bed and wake up in the middle of the night not being able to breathe, you know, that sort of thing. [CF-01]

In both groups a number of mothers made major career decisions to accommodate the level of vigilance that they believed a necessary part of mothering their child. The demands of ADD seemed more likely to lead to both physical and emotional exhaustion than those of CF. Some examples follow:

Are there additional physical demands on you in dealing with your special child? Yes. Physically getting up early and making waffles for breakfast. Doing more work at school than anybody else. Going swimming at 4:00. Changing two little boys in the changing room. Trying to make them not slip on the floor. You can't, taking them to the barn, making sure a horse doesn't kick them, saddling the pony, taking them both out in the corral, making sure that one isn't running off . . . I look at some of the . . . mothers of other kids, saying, "Geez, I'm so tired," and I'm thinking, "You don't even know what a tiring day is. You have no

idea." . . . When my kids get home at 2:00, I have to know what they're doing every minute, not because I want to, but because I walked into the kitchen last week, with the windows open and I can see what's happening, they had the hose and they're spraying things out in the lawn and they're jumping through it. Geez, I missed the cars going down the street and my older son squirting through the windows of the car at the businessmen . . . I messed up with my son this weekend when I put him in bed at my parents and the fax machine and my father's phone was in there. He called 911. He had the [city] police come to my door. Because he just couldn't help himself for dialing 911 and calling up . . . Jesus. I should have never put him in my parents' bed just to start off sleeping so I could separate him from his brother. And I've known for awhile that he was sort of hung up on calling 911. I mean, and I had defused it a few times by walking around with the cellular in my pocket. You forget one time, you know. And I could go on and on. Plus, you've got, you know, everything has to be so organized. [AD-19]

While the terminal nature of CF leaves mothers feeling powerless, the persistent unacceptable behavior of ADD results in anger, self-recriminations, and occasionally aggression in the family. Many ADD mothers commented on how easy it would be to abuse an ADD child, and some recounted a period in the family where the parents policed each other because they were concerned about losing control.

[Spanking him] didn't make any difference. And we got to the point where I said, "That's it. We're not hitting this child ever again." Because it didn't matter. He almost would push you to the point so that you would so that afterwards he got to get up in your lap and you felt guilty, he knew you felt guilty, and you were both crying. And he saw that and he knew that and I mean, it's like that's it. And when I made that statement, and I made the mistake of saying it to my mother, she went, "Well, that's the problem." I said, "Mother you don't understand. You don't understand." So we went through probably two and a half years, where we policed each other. It was a mutual agreement, and we would not smack, hit any way, shape or form, P-., ever. Now I will take him and say, "All right, drop

your drawers, you know you shouldn't have done that to your brother." You know, that kind of stuff. But it had got to a point where it was not healthy for anybody in the family with him especially. He was a very angry child for awhile, especially going through kindergarten, and I think that was part of the reason, because Mom had lost control, Dad had lost control, the whole family. [AD-08]

These parents had little sense of personal effectiveness and little sense of control in a primary life role (mothering). Their child's behavior collided with their social values and social expectations. The behavior of their child led to condemnation of themselves as individuals as well as exclusion of their child from social situations.

I can remember one time I came to the fitness center and I brought M-. and the woman was waiting for me outside up at the child care thing and just told me that, actually she told me that he was a spoiled brat, or something, he wouldn't sit still, and she was like really mad, and I just started crying. Because I just thought, "My God." And I went home and I told my husband. Of course, he wanted to call the owner, and da, da, da. And I'm going, "You're missing the point here. Nobody wants him around." And it wasn't, ah, when we went through the discipline thing, you know, trying to, you know, just spank him. Well, spanking did not do anything. I remember one time that, oh, he came to blows because we had gone to Disney or somewhere like that and this kid climbed, in a flash, he ran and he climbed over a barrier, you know, and there was like a steep cliff and that would have been it. And my husband's first reaction was to grab him, spank him. Of course, everybody's looking, you know. And you feel horrible. And the kid will turn around and five minutes later was doing something equally as, and I'm going, it just spoiled the whole vacation. We came home early. It was horrendous.[AD-08]

So for ADD mothers, more so than CF mothers, the situation is beyond the state of an ordinary resolution. The child's behavior problem may be lessened slightly by

extraordinary parenting, but only slightly. Unlike the CF mothers who felt rewarded socially and emotionally for their extra efforts, the ADD mothers were extending themselves to an extraordinary degree for their child and still receiving social sanction and trying child behavior. Having exhausted their repertoire of discipline strategies, these mothers reported everything from exhaustion to rage. In three of the families interviewed child abuse had actually occurred and been reported to local child protection authorities.

Looking at occupational behavior frameworks it is difficult to label this problem, but it is clearly a negative impact on the mother's sense of personal control. Although impacting the volition subsystem, it is unlikely that the disruptive behavior of their child will affect either values or interests.

Summary

Each of the theoretical models is useful for bringing meaning to the data. The RMFSA was useful in directing the type of data collected to reflect knowledge about family function and perception of stress in families. This model explained little, but offered a basic format for data analysis that was useful in considering the other models. Normalization was an emergent theme that was well explained by earlier studies on this behavior. That ADD did not lend

itself to normalization theory was an interesting finding. This seems to be because normalization is, in effect, the successful management of a social facade. The disorder in ADD is social, and not easily hidden through simple cover-up strategies. Perhaps the inability to normalize offers one explanation for the high perception of demands and negative outlooks common to mothers of children with ADD.

Occupational behavior theory adds the individual perspective. This theory is useful in looking at the mother in interaction with her "environment." The concept of environmental press and the impact of threats to the mothers' sense of personal control on the attitude and resiliency of the individual are helpful. The inclusion of all objects, social groups, and cultural influences in the construct "environment" does not lend itself to testing this aspect of the theory.

CONCLUSIONS

Discussion

The findings of this study support the thesis that behavioral disorders of childhood result in more day-to-day maternal stress than chronic childhood medical conditions. An important theme in this study is the importance of child performance on a mother's sense of competence. The focus on the mother role includes "supermom" expectations in relation to the child's disability. In both groups mothers extended themselves to provide what they perceived as their children's needs. Most of their daily routines were child-centered. Decisions about everything from personal hygiene to paid employment were based, in large part, on meeting their child's needs. The goal of all mothers in the study was to be a "normal" family. It was in their ability to reach this goal that the major between group differences were identified.

CF Findings

Mothers living with CF responded in ways consistent with other research on chronic illness. They had many additional daily demands, but they were routine and soon became "normal." These mothers report close and positive family relationships and personal growth associated with living with CF. The biggest stress faced by CF mothers was emotional: the fear of their child's untimely death. This theme mirrors the "chronic sorrow" pattern described by Darling (1987). Many mothers of children with CF chose to leave the work force rather than leave their child in day care. They were generally reluctant to use child-care, even when the child was doing well. CF mothers said they "treasured the family moment" and were very child-focused in their daily choices and routines. My over-riding perception of the CF mothers was of "super-moms" who did everything from serving hot well-balanced breakfasts to turning down the sheets at night.

The CF group had fewer fiscal resources, but far greater social resources than the ADD group. Importantly, the CF children were socially identified as "sick." Small deviances are socially tolerated and efforts to be "normal" considered valiant. There are good societal resources for family education, counseling and treatment programs for the child. The treatment of CF can be easily routinized and

lends itself to normalization. While there is no way of judging costs and benefits as Robinson (1993) and Darling (1987) do when comparing a terminal and a non-terminal condition, the CF mothers seemed to have a more positive view of themselves, their child, and their social network than seen with ADD. These mothers repeatedly said "we just live one day at a time." Focusing on normal routines and immersing themselves in sometimes extraneous mothering activities, these mothers tried to deal with the chronic sorrow of CF.

ADD Findings

The responses of ADD mothers were not typical of the patterns commonly described of families having a chronically ill child. Like CF, they had many child-centered daily demands. Unlike the medical demands of CF, the demands were caused by impulsive and atypical types of behavior. Behavioral challenges feel more personal and are more likely to conflict with maternal perceptions of competence. A common response of ADD mothers when asked how people perceive their child was "Lady, why can't you control your child." Each time I heard this it seemed that the mothers were asking the question of themselves. There was no instance in this study in which any ADD mother was less than committed to her child. Wanting all that every "good"

mother does, but challenged with an atypical child, these mothers also had "supermom" expectations. Most stretched all their personal resources to help their children. In fact, ADD mothers who were not employed full-time reported far more school involvement than the CF mothers. Most ADD mothers had worked out some kind of strategy to minimize conflict in the home, and were sensitive to the individual needs of their children.

Because ADD children are not "sick" children, parents dealing with the disorder are not routinely afforded lenience in social expectations. A mother asking a favor because her child has CF is never discounted with "Oh, everybody has that these days !" The atypical and often unpredictable behavior associated with ADD interferes with the development of positive normalization behaviors. When a mother was able to maintain a fairly organized personal routine she tended to report a higher sense of control and competence. ADD mothers expressed much more emotional exhaustion and a need for "alone time." Many mothers in this group described work outside the home as a refuge. Mothers working outside the home emphasized the need for the extra income and often expressed a desire to have more time at home.

The higher fiscal resources for the ADD group in general do not compensate for the lack of social recognition and support. For many, the simple act of diagnosing the

child put a physician on the social support list. Mothers with biological ADD children had far less support from both their immediate and extended families. In particular, they had far less emotional support. Chronic sorrow does not describe the emotional strain on mothers of children with ADD. Chronic turmoil better describes the unsettled vigilance and defensiveness maintained by these mothers. Their inconsistent treatment in both school and health care systems adds to the conflict.

Darling (1987) concludes that "availability of resources is the most important determinant of family adaptation, regardless of the nature and degree of a child's disability" (Darling, 1987, p. 45). This study elaborates on Darling's finding. This study suggests that availability of family and medical support are more important than fiscal resources. In the case of CF, where the child's access to care is not limited by income there was far greater adaptation than found in the ADD families with higher overall incomes. In ADD, income enhances access to health care and was the most commonly cited reason for working outside the home.

Most ADD mothers are acutely aware of the lack of social and family acceptance of their child. This was a source of sorrow and concern. The emotional and social resources of both groups were largely limited to family members, but in ADD the family network is very small. How

much the lack of social resources contributes to their difficulty adapting is impossible to determine from this research, but it is believed to be a major determinant of each mother's outlook and sense of competence.

Implications for Theory

This research affirms the relationship of normalization and positive maternal interactions. Most studies of normalization focus on a cost/benefits decision making approach. In cost/benefit analysis the focus is on why some individuals within a disability group are more successful than others. Looking at the two groups, normalization efforts were certainly more costly for mothers with ADD. In focusing on life "as normal" CF mothers were following medical prescription, while earning social support. Life "as normal" gives the CF mothers a day-to-day focus that helps alleviate the "chronic sorrow." ADD mothers are thwarted at every step in constructing a picture of life "as normal." Their child care demands are not routine and are not solved by prescriptive medical interventions. ADD mothers quest for the book, or article, or therapist that is going to provide the golden key that will solve their problems. What these mothers feel parallels the social psychological construct "learned helplessness" (Kaplan & Sadock, 1988). Learned helplessness is that pattern of

behavior that occurs when an individual is exposed to unsolvable problems. In other words, learned helplessness reflects the sense that you have little control of things. That nothing you do makes much difference.

Sense of personal control was the over-riding difference between the CF and the ADD groups of mothers. The CF mothers were able to adapt and achieve a semblance of life "as normal" because the behaviors that needed to be organized were largely under their control. ADD mothers wanted life "as normal" but they had no control of the behaviors that needed to be organized. Ritalin, much touted as a "Godsend," offers them some control of the erratic behavior that is so unsettling. Most mothers said Ritalin helped their child. Many also said Ritalin for their child helped them as mothers.

A sense of being in control is central to positive adaptation in both the normalization theory and in the ecocultural approach. The literature lists specific threats to normalization that include parental denial, accidents, conflicts over division of labor between family members, difficulty managing medical equipment or procedures, identity change, and disruption of routine. Although many of these threats are not applicable to the individuals in this study, each of these threats represents a way of avoiding or losing control.

In this analysis the constructs of environmental press and personal causation from MOHO help to identify potential threats to adaptation in general. The information from MOHO is intervention oriented and offers clear implications for the behavior and strategies of health care providers.

Implications for Health Care Providers

The CF mothers in this study were generally pleased with their health care providers. Their care was centralized in a specialized regional clinic that included an interdisciplinary team. They were frustrated with the frequent change in attending physicians but believed they were receiving the best possible care for their child.

The things that CF mothers reported that would help them in dealing with the care of their children were increased flexibility within the public school systems to deal with their child's frequent absences, and a waiver of the need to go the principal's office to get enzymes before lunch. Some of the adolescent children kept their condition secret from peers and were non-compliant rather than be stigmatized by visits to the office.

The needs of the ADD mothers were more complex. The initial referral and diagnostic process was frustrating for most. The lack of community consensus on when and where to refer children suspected of ADD was prevalent. The mothers

who had most successfully negotiated the diagnostic process were guided by friends with ADD children or by inside information available to the parents working in the health care system. The medical support of many ADD mothers was limited to diagnosis and medications. The availability of access to interdisciplinary care was linked to family income and the type of private health insurance carried.

Extended families were perceived in both the CF and the ADD groups as the most viable source of respite from maternal vigilance. Biologic mothers of ADD children had far fewer supports in their extended families than CF or adoptive ADD mothers. With few resources for respite and affirmation these mothers were likely to isolate their family socially rather than deal with implicit and explicit social criticism. It was exclusively in biologic ADD mothers that comments were made like "I have no life" and "the life is being sucked right out of me."

The social stigma of poor parenting was a pervasive theme in the ADD transcripts. Even as they defended that their child had a neurobiologic problem, many mothers implicitly questioned their ability to respond and succeed as a "good mother." The need for high vigilance in child care and the unpredictability of demands in ADD left the mothers feeling "out of control." This lack of control seems to be the basis for the negative feelings and sense of personal distress. Ambivalence about the use of medications

and inconsistent information about the causes and effects of the disorder added to the stress and concerns of ADD mothers.

When asked what would be the most helpful to them, ADD mothers generally cited increased social understanding of ADD, and increased options for their atypical child to perform and succeed socially. Contrary to the pictures painted by the critics of ADD as a medical problem, none of the mothers in this sample were shirking responsibility for their child or their child's behavior. First and foremost these mothers wanted their children to succeed. Most were also painfully aware that their own efforts had limited effectiveness and wanted help for both their ADD child and their family. The most outstanding problems of ADD children on Ritalin were academic difficulty and inappropriate social interactions. For most parents, there was limited school support and little health insurance coverage for these types of interventions. When asked what would help, the most common reply was insurance coverage for more than medications. The next most frequent concern was school reform. Specifically, ADD mothers wanted a more structured school environment with fewer "take home" assignments. Mothers were particularly frustrated by teachers who did not direct or respond to their child's special needs at school and sent home the unfinished work from the school day as additional homework. It was uniformly reported that

evenings were difficult times for children with ADD and that it was a painful time to extract academic work.

Health care professionals were the most widely reported support providers for mothers of children with ADD. Even small amounts of time spent listening or providing information about the condition were highly prized by these mothers. The interactions with the health care providers were far more emotionally important to ADD mothers than they were to CF mothers. A repercussion of this is that health care providers need to be sensitive to the vulnerabilities and stresses of living with ADD. In this study ADD mothers tended to gloss over specific difficulties unless specifically questioned. Perhaps in trying to maintain an appearance of competence, it is likely that the degree of the problems a given mother faces may be under-reported.

Clinicians are in a powerful position to affirm and guide mothers of children with ADD. Based on the findings of this study, parent support training emphasizing realistic personal expectations in their parenting roles is imperative. Some specific recommendations include:

- * Identify as a clinician your definition of good parenting so that parents know explicitly what is expected of them.
- * Question parents about the descriptions they offer. Some ADD mothers gloss over their children's behaviors either to avoid being tiresome, to avoid

revealing their perceived failures, or to avoid being overly negative about their child. Without a clear picture of the child's behavior you will be unable to support and guide that parent.

- * Help parents identify their personal mythologies about "good parents" and offer suggestions of ways to alter these to allow personal control and parent behavior goals rather than a focus on child performance.

- * Help couples focus on shared realities in the family rather than ideals. Help parents construct a social niche that is both possible and acceptable to them. This will aid the sense of personal control and ultimately the process of normalization.

- * Mothers who had scheduled some personal time for exercise or other recreation were more positive than mothers who were totally child focused. The costs of personal time seem greatly outweighed by the benefits in the mother's sense of control.

Unfortunately, focusing on the real situation and setting realistic personal goals is a task some parents find depressing. They grieve in feeling that they are lowering their standards, parents feel that they are catering to the child. Parents need support in working through the best and most realistic expectations for their family. Emphasizing a positive balance of work, child care, and personal care

expectations helps reduce the feeling of compromise. In creating a more positive perception of themselves, the mothers are more likely to be positive in their interactions with the child.

When they are available, health care providers should encourage the use of friends and religious counselors as supports. Efforts to reduce the unwanted social isolation of families should also result in more positive outlooks. Many mothers complained about the lack of this kind of support but were so caught in endless child-demands and exhaustion that they had not sought out this type of support. Support groups were seen as informational rather than providing emotional release. Many ADD mothers inconsistently attended these, but few listed them as a source of support.

Limitations of this Study

This study had a small convenience type sample. These findings describe only the population sampled, they cannot be generalized to the larger population. The ADD sample is unique because of the high income level and high incidence of ADD children in adoptive homes. This region does offer specialized interdisciplinary intervention programs for persons with ADD which may not be available in other areas. It is possible that in other communities the problems

associated with diagnoses and treatment of ADD would be much greater.

Data were missing in some interviews for a number of reasons. Two CF interviews were cut short by time constraints, and CF mothers in general were less descriptive of the family story. An additional CF interview was completed to adjust for this difference, but it yielded no new information or insight into themes.

All diagnostic information was gathered from the mothers. While there is little concern about the basic child diagnosis of either CF or ADD, additional diagnoses may not have been included. This is a particular concern in ADD where secondary psychiatric diagnosis were common. Although asked if the child had any other diagnosis, few mothers listed any. Studies indicate that ADD children with oppositional defiant or conduct disorders are highly disruptive to family function. Failure to isolate these cases may artificially lower the ADD performance on all family measures.

This research focused on family interaction in the present. Most of the CF mothers reported a long stable period following their child's diagnoses. This pattern was similar, but to a smaller degree in ADD. Because the ADD mothers had had far less time since diagnoses their experience with their child on medication was more limited. The impact of years on undiagnosed uncertainty are likely to

be a pre-existing vulnerability for ADD mothers. The sense of exhaustion and lack of control may be alleviated with the use of medications, but the emotional sequelae remain.

Another limitation was the referral sources for subjects. The CF group was drawn primarily from pulmonary clinic attendance. Because all CF children in this region attend this clinic the sample was not preselected in terms of parent income or behavior. The ADD group was originally to be drawn from the Morris Center clinic that specializes in the treatment in ADD. As the differences in group incomes became obvious, subjects were actively recruited from regional parent support groups. This brought the incomes of the two groups closer together, some higher income CF families were in the CF support group and some lower income ADD families were in the ADD support group. The problem with relying on support groups is that it preselects parents that are actively seeking help or support. Those purported "bad mothers" who use ADD as an excuse for their poor parenting are not likely to be associated with either a specialized private clinic or a support group.

Mothers were not asked about their or their spouse's employment. Information about employment was drawn from comments made by the mothers and from their report of daily routines. The researcher was left with the impression that ADD families were working more, often two to three jobs to

pay for their child's care, but this is not reflected in the sketchy data available about employment. This limits analysis of this important area of adult life.

Directions for Further Research

Normalization and ecocultural theories offer many possibilities for the extension of knowledge about atypical children and family responses to atypical child demands. The consideration of different groups experiencing behavior problems would extend the knowledge about the importance of role expectations and the ability to routinize interventions.

This study suggests that child treatment interventions should be ideally be enmeshed in family routines. In fact, intervention time would be productively used to foster family routines. Studies considering therapeutic interventions considering "normalization" could be great asset to clinicians in determining best care.

The distinction between adoptive and biologic mothers in ADD warrants further investigation. This was an unexpected finding and no support was found for it in existing literature. The tendency for families with ADD to have high incidence of other social and emotional problems is well documented. There is a widespread perception in the medical care community that a high percent of ADD children

are adopted, but no literature was found addressing this possibility. Understanding this would lead to a better understanding of the effect of ADD on the extended family and to indications of the type of intervention that would be most productive for a particular family.

In both groups as the impaired child entered adolescence the mothers reported increased denial of the condition and increased concern about the child's personal responsibility. This was especially problematic in CF because the disease condition was worsening as the child began to refuse or avoid interventions. An increased focus on chronically impaired adolescents would help develop strategies to support these families while helping the child develop the personal skills need to succeed in adult life.

The research presented here suggests that behavioral disorders impact mothers in a far different way than medical disorders. This study is consistent with earlier research in emphasizing the importance of social and health resources in the perception of family well being. Further research is needed to focus on problems and adaptations of the family in the presence of chronic disability.

The differences perceived in dealing with the two disabilities in this study is summarized by the comments of the mother with one child having each disability:

Do you have concerns for your special child, like college or future, that you do not have for other children in the home? Yes. With [my child with ADHD]

it's all of it. I wonder if he's ever going to be able to control it, instead of letting it control him, or if he has to be on this medicine forever, or if he's going to be able to hold a job down. If he gets a job to where he's sitting all day, he'll never make it. He has to be moving constantly. But with [my child with CF] it's not really a concern. I know his can be pretty much kept under control as long as he stays on the medicine and you know, I understand that he's going to die one day, but I'm hoping that it will be a very long time. [CF-AD]

"Lady, why can't you control your child?"

This study was important in showing differences in the impact of behavioral and medical behavior problems on the family. It supports that families with atypical children idealize and work toward being "normal". For mothers the sense of being "in control" greatly diminished their perception of stress. Childhood behaviors or illnesses that were outside the mother's ability to manage were highly stressful and disruptive.

Mothers were found to interpret and respond to their child's problems very personally. Some mothers reported that the questions asked by health care providers and teachers felt threatening to their competence as mothers. In addition to the social censure caused by disruptive child behaviors, these behaviors were threatening to the mother's sense of competence and personal control.

Mothers of children with ADD seem to have internalized the comment "Lady, why can't you control your child ?" by

being very self-critical and critical of all others interacting with the child. Impulsive and aggressive behaviors seemed to be more stress producing for mothers than high activity levels and poor attention. The mothers who were able to define themselves as distinct from their child and the child's special needs were more positive and better able to respond to the child's needs.

In attempting to describe and evaluate the differences between mothers and those mother's perceptions of family and personal stress, the ambiguity of the "mother" role became evident. The idealization of the parent role for women seems distinct from that common to men. This distinction parallels the gender difference in the meaning of paid work described in the literature (Thompson & Walker, 1991).

These authors state:

Women typically say "Work is what I do, not what I am," while men typically offer their occupation first . . . Men are better able than women to keep paid work and family as separate spheres of life (Thompson & Walker, 1991 p. 81).

It seems that women with children define themselves as mothers first. Mothers are what they are, not what they do. It has been argued that masculinity is identified with success in paid work (Bernard, 1981; Thompson & Walker, 1991). Perhaps womanly success is identified with "good mothering" rather than employment.

Success in paid work can be measured fairly objectively, in terms of either income or productivity. In most cases, work behavior relates to these measures of success. As noted earlier, parenting success is subjectively. Rather than measuring specific maternal behaviors, successful mothering is measured by child outcome. Extending this argument then, men have much more potential influence on the social measures of masculinity than women have on social measures of womanly success. This is especially true when a child has a behavioral disorder like ADD.

This brings into question some existing sociological beliefs. The mothers in this study were intensely involved with their child. Many described their spouse as "a good father" but "not really there" in dealing with the child's special needs. Some mothers described their spouse as "not bonded" to their child, or only able to "bond" when the child got involved in organized sports. In both samples there were instances where the mother's behavior was so intense and her performance expectations so high that she actually pushed away others hoping to help, including the child's father.

Are fathers really ". . . better able than women to keep paid work and family as separate spheres of life (Thompson & Walker, 1991 p. 81)", or is their immersion into paid work their perception of being a "good provider"

for their family? Do maternal behaviors limit the fathers confidence and development of skill in caring for their child? Because he is likely to identify with his employment role in addition to the parenting role, is the father able to be objective in dealing with the child's problems? In what ways does fathering behavior uphold the "life as normal" story. And importantly, are normal mothering behaviors exaggerated in chronic childhood conditions? Fathers were excluded from this study to avoid gender differences in perception of stress. Without reports from these children's fathers this line of thought is purely conjecture.

This study offers insight into mothers' behavior and provides suggestions for change in the orientation of communication between service professionals and parents. This study also reveals the need to do further research in order to understand the father's role and the parental dynamics involved in dealing with chronic childhood conditions.

APPENDIX A
THEORY CONSTRUCTS EMBEDDED IN THE INTERVIEW

1. Child disability characteristics
 - a. Type and manifestation of disability
 - i. Age at diagnoses
 - ii. Stress/guilt prior to diagnoses
 - iii. Add
 - (1) With hyperactivity
 - (2) Without hyperactivity
 - iv. Cf
 - (1) Perceived as healthy
 - (2) Perceived as fragile
 - b. Feelings/concerns about child's disability
 - c. Feelings/concerns about child's future
2. Pile-up of demands
 - a. Family stressors
 - i. Change in employment status
 - ii. Change in living situation
 - iii. Illness or death in family
 - iv. Emotional problems in family
 - (1) Violence initiated by adults
 - (2) Violence initiated by child
 - v. Childcare problems
 - vi. Medication/intervention controversies
 - vii. Hospitalization
 - b. Family strains
 - i. Presence of more than one disabled family member
 - (1) Adult or child with add
 - (2) Other
 - ii. Presence of adolescents in the home
 - iii. Increased arguments
 - (1) With spouse
 - (2) With children
 - (3) Between children
 - iv. Difficulties with health insurance/health care providers
 - v. Family income impacted by disability
 - (1) Mom's work or career choice impacted
 - (2) Unreimbursed medication or intervention
 - (3) Other
 - vi. Child with academic problems
 - vii. Child with atypical/unpredictable behavior
3. Family values and demands
 - a. What is "normal"?
 - i. Child's performance expectations

- ii. Child's health expectations
 - iii. Child-focused routines/priorities
 - iv. Mom-focused routine/priorities
 - b. Mother's outlook/mood
 - c. Finds support in faith
- 4. Family and friend support
 - a. Extended family support
 - i. Childcare
 - ii. Emotional
 - iii. Financial
 - b. Friend and community support
 - i. Childcare
 - ii. Emotional
 - iii. Financial
 - iv. Academic
- 5. Family resources
 - a. Family income
 - b. Health insurance
 - c. Public support
 - d. Other
- 6. Family routines
 - a. Perception of order
 - b. Mother's occupational balance
 - i. Need for vigilance in child care
 - ii. Personal expectations
 - c. Household maintenance
 - d. Time use
- 7. Community support
 - a. Friends
 - b. Neighbors
 - c. Health care providers
 - d. School providers
 - e. Community
- 8. Financial resources
 - a. Health insurance
 - b. Public support
 - c. Family income
 - d. Child support
 - e. Trusts/ gifts/other
- 9. Family
 - a. Family structure
 - i. Adults in home
 - ii. Children in home
 - b. Medications
 - c. Interventions
 - i. Special therapies
 - ii. Special tutoring
 - d. Emotional demands
 - e. Physical demands
- 10. Accommodation to child
- 11. Accommodation to change/challenges

- 12. Moods/tensions in home
- 13. Family routines
 - a. Recreation
 - b. Bedtimes
 - c. Meals
 - d. Chores
 - e. Homework
 - f. Normal housework
 - g. Therapy/tutoring
 - h. Discipline
- 14. Perceived impact of disability
 - a. Finances
 - b. Relationship problems
 - c. Siblings
 - d. Communication
 - e. Violence
 - f. Time shortage
 - g. Vacations/social outings
 - h. Child care
 - i. Extended family

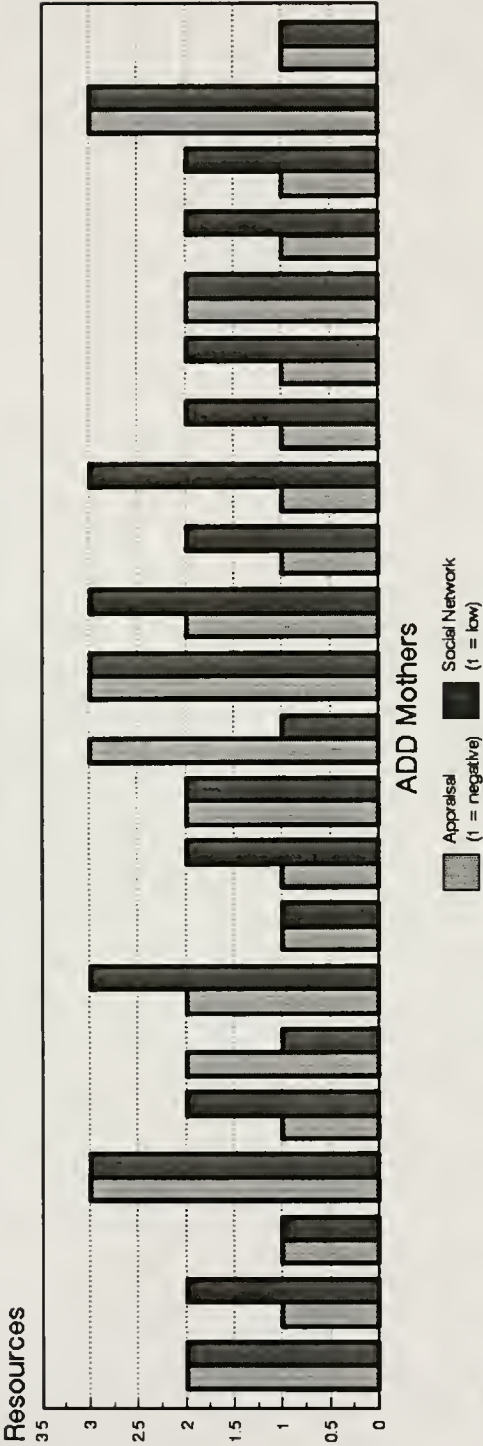
APPENDIX B
CODES IMBEDDED INTO INTERVIEW TRANSCRIPTS

[ADULT WITH ADD OR UNDIAGNOSED CHILD]
[HEALTH INSURANCE/HEALTH CARE]
[COMMUNITY/SOCIAL ISSUES]
[DISABILITY/FUTURE]
[EDUCATIONAL PLACEMENT-DISABILITY RELATED]
[FRIEND/FAMILY CHANGE]
[CHILD MENTAL HEALTH PROBLEM]
[HELP/SUPPORT]
[INTERVENTIONS/EXPECTATIONS]
[VIGILANCE-MOM ONLY]
[POSITIVE KID NOTE]
[LABELLING/INVISIBLE DISABILITY]
[MEDICATION COMMENTS]
[NORMALIZATION/CHAOS]
[CHILDCARE LIMITS]
[PROBLEMS AT SCHOOL-DISABILITY RELATED]
[EMOTIONAL DEMANDS]
[RESOURCES/FINANCES]
[SIBLING ISSUES]
[THERAPY/PHYS-DEMANDS]
[CHILD-FOCUSED ROUTINE/PRIORITIES]
[VULNERABILITY/STRESS]
[MOM'S WORK OR CAREER CHOICE IMPACTED]
[MOM-FOCUSED ROUTINE/TIME]
[I FEEL GUILTY../WHY ME ?]
[CHILD VIOLENCE-ABUSE]
[VIEW OF DEMANDS]
[SENSE OF CONTROL]
[ROLE EXPECTATIONS]
[PRESCRIPTIVE ACTION]
[*GOOD STORY]
[*POSITIVE OUTLOOK]
[*NEGATIVE OUTLOOK]
[*FAITH]

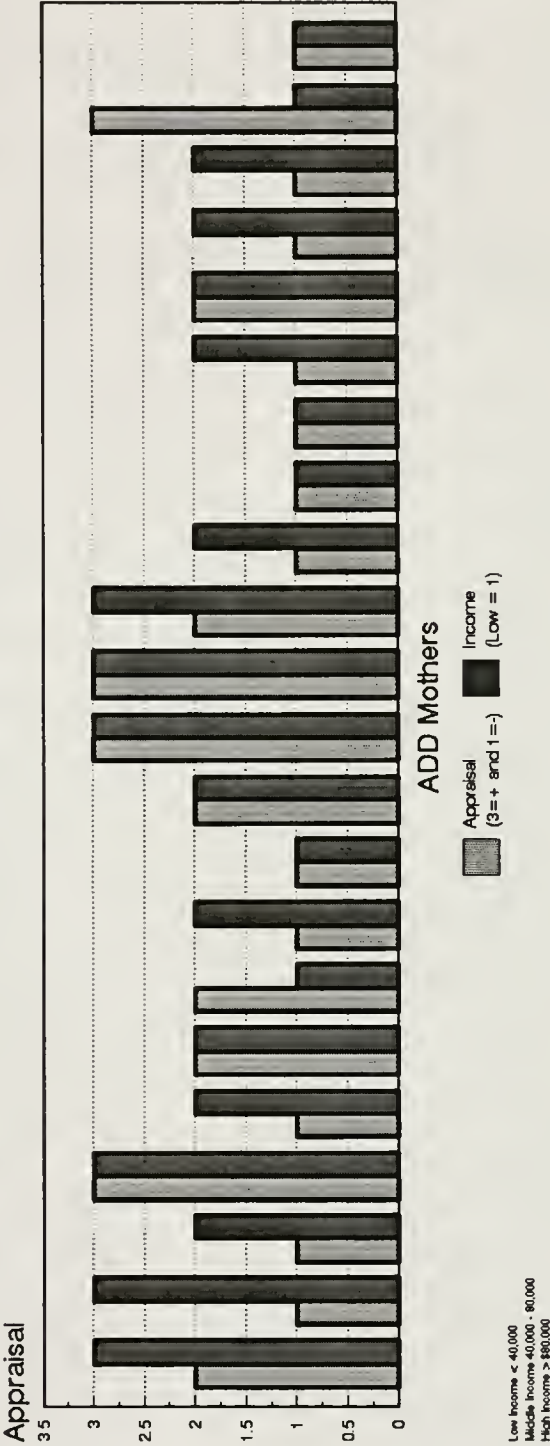
[ADOPTED CHILD]
[MOM-MENTAL HEALTH HISTORY]
[MOM EMPLOYED]
[NATURAL CHILD]
[PUBLIC SUPPORT ONLY]

APPENDIX C
ADD APPRAISAL GRAPH- SOCIAL NETWORK & INCOME

ADD Appraisal: Social Network

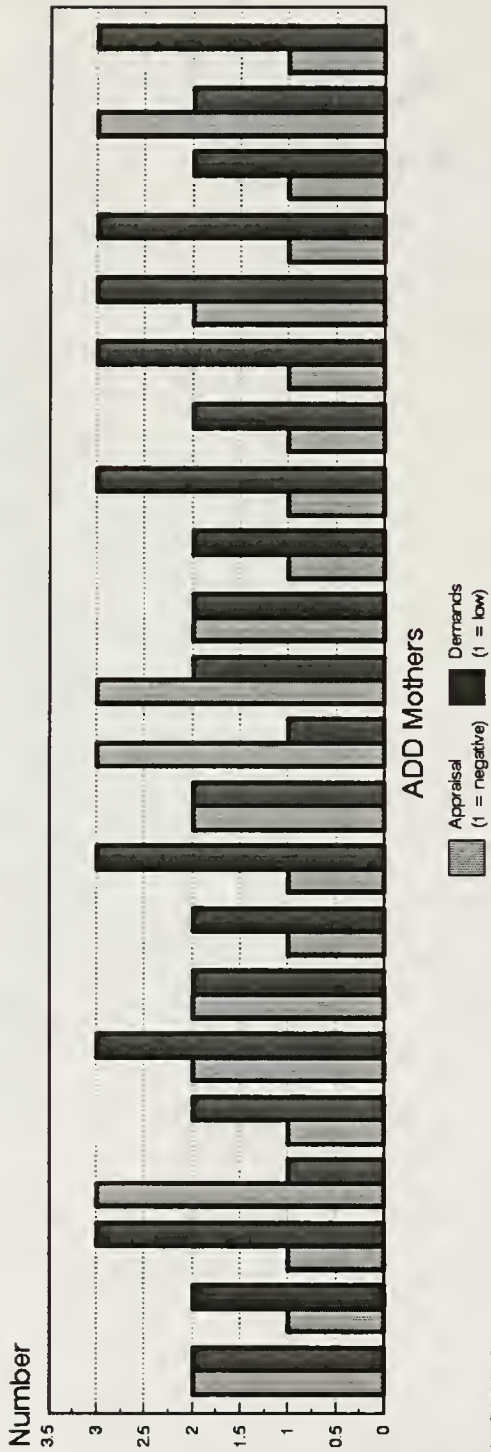


ADD Appraisal - Income

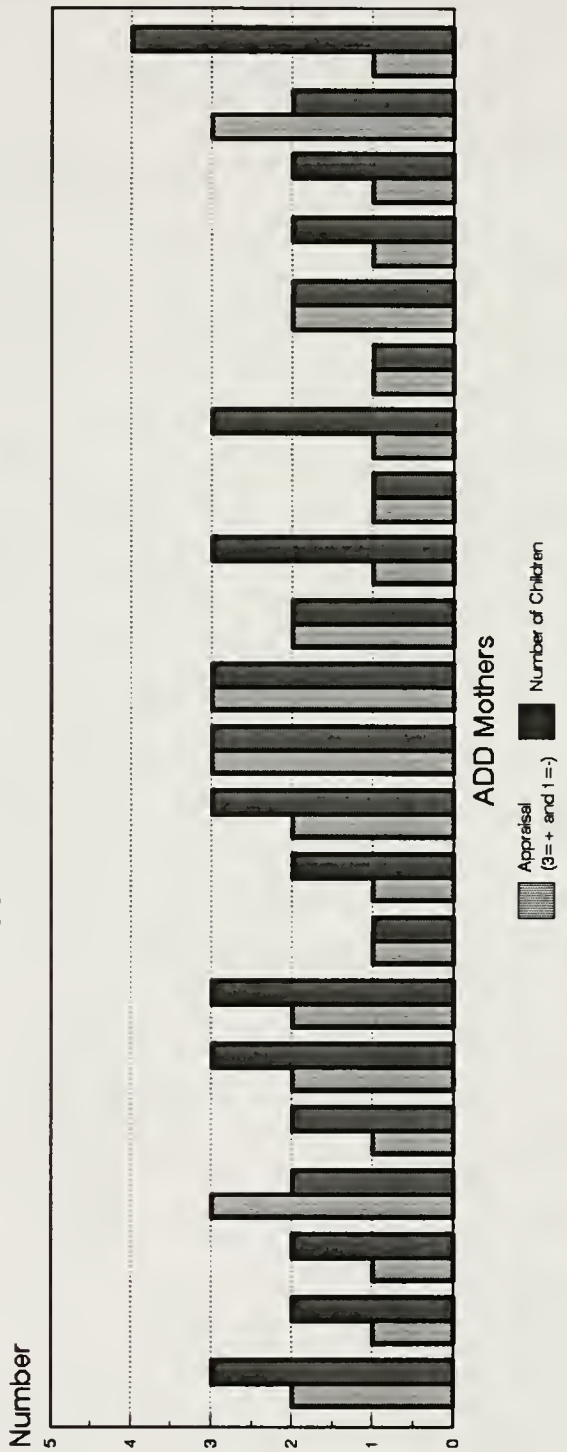


APPENDIX D
ADD APPRAISAL GRAPH- DEMANDS & NUMBER OF CHILDREN

ADD Appraisal - Demands

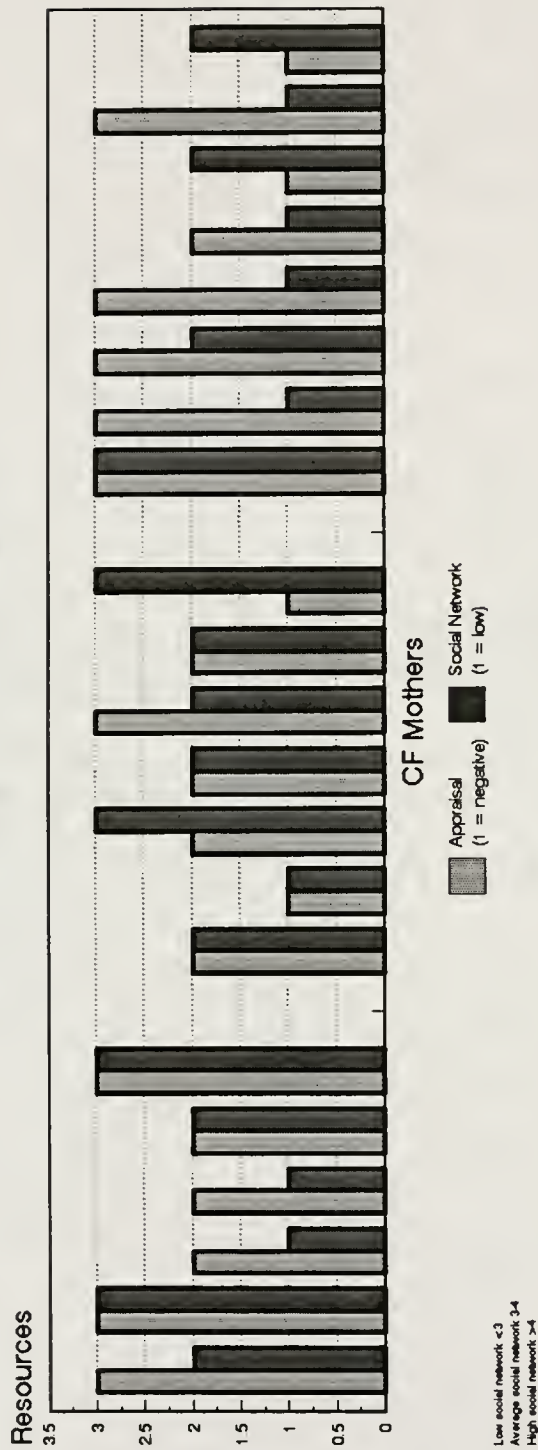


ADD Appraisal - Number of Children

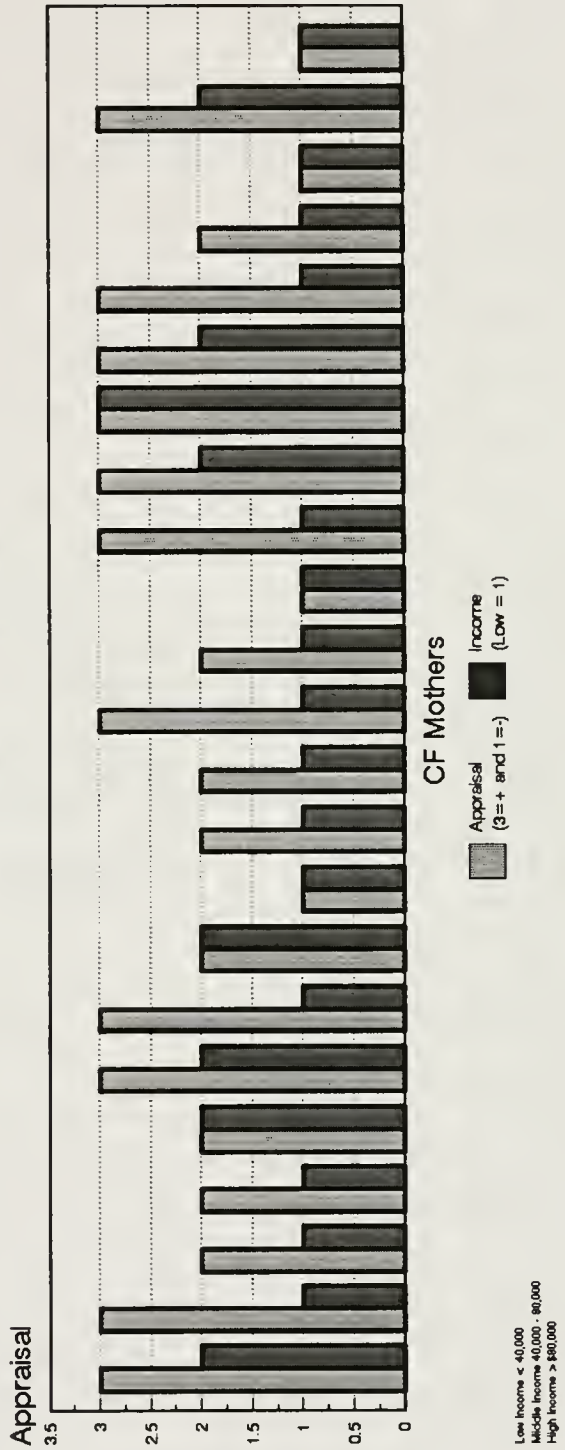


APPENDIX E
CF APPRAISAL GRAPH- SOCIAL NETWORK & INCOME

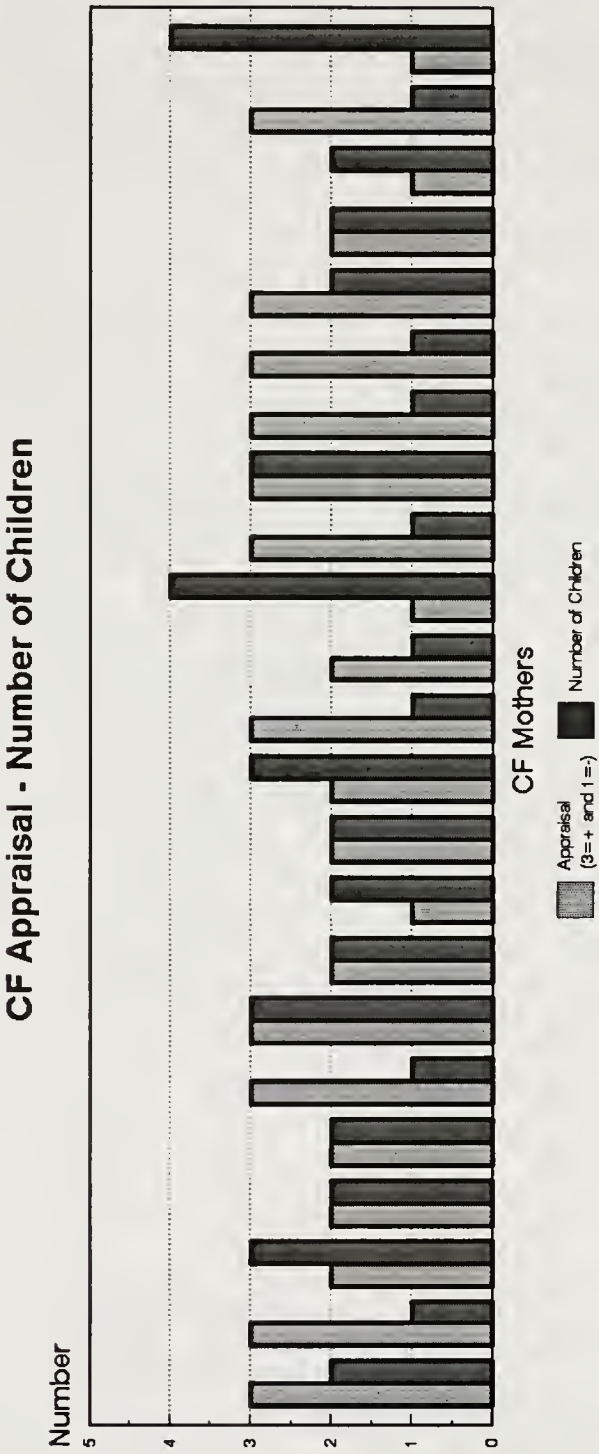
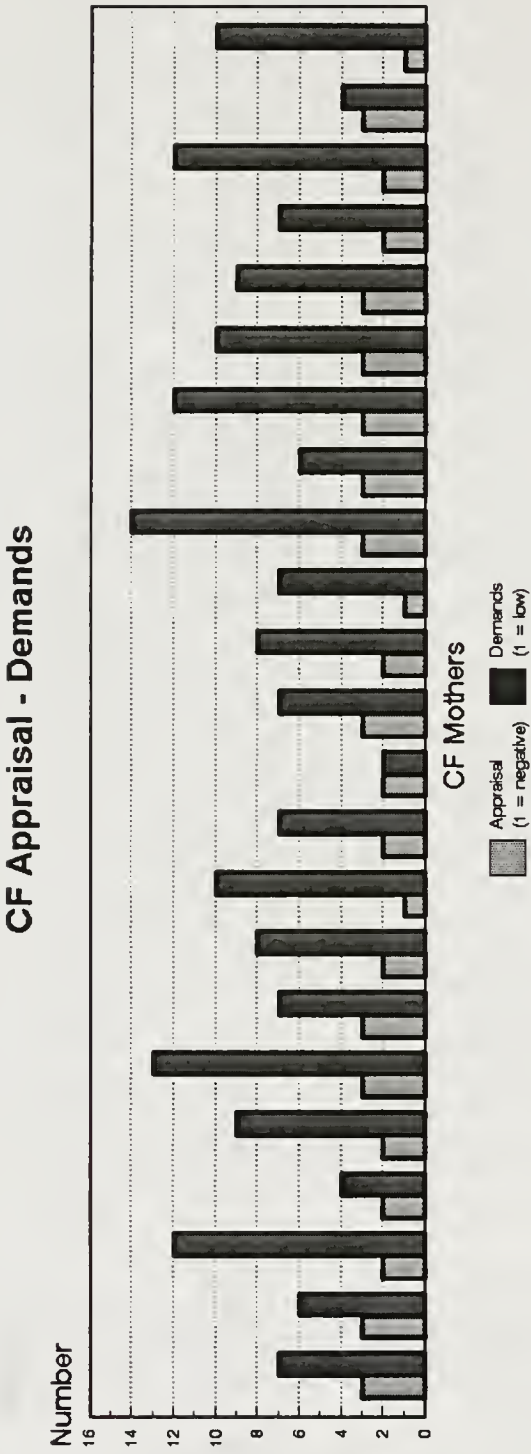
CF Appraisal - Social Network



CF Appraisal - Income



APPENDIX F
CF APPRAISAL GRAPH- DEMANDS & NUMBER OF CHILDREN



LIST OF REFERENCES

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by human CFTR. Science, 266(5191): 1705-8.

BIOGRAPHICAL SKETCH

Anne Frances Cronin was born in Charleston, West Virginia, and moved to St. Louis, Missouri when she was 12 years old. She earned a B.S. in occupational therapy from the University of Missouri in 1978. While working as an occupational therapist at St. Louis Developmental Disabilities Treatment Center in St. Louis, Missouri, Ms. Cronin earned a M.A. in health services management from Webster University in 1981.

Ms. Cronin's experience as an occupational therapist has focused on the treatment of children and families dealing with a variety of chronic conditions. This clinical experience led to Ms. Cronin's observation of the distinctive parental distress associated with ADD.

In addition to her pursuit of a doctorate in medical sociology, Ms. Cronin's scholarly work includes two small grant funded projects and several publications in the field of occupational therapy.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



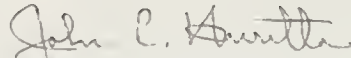
Constance L. Shehan, Chair
Associate Professor of
Sociology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



Lee Crandall, Cochair
Professor of Sociology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



John C. Henretta
Professor of Sociology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



Marjorie A. White
Professor of Nursing

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



Kay F. Walker
Professor of Occupational
Therapy

This dissertation was submitted to the Graduate Faculty of the Department of Sociology in the College of Liberal Arts and Sciences and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August, 1995

Dean, Graduate School

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